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School Experiences of Successful Adults with Blindness

by

Dianne Wynne McConnell ©

A thesis submitted to the Faculty of Graduate Studies and Research
in partial fulfillment of the requirements for the degree of
Doctor of Philosophy

in

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67 Woodside Crescent
Spruce Grove, Alberta
T7X 3E6

University of Alberta

Faculty of Graduate Studies and Research

The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies and Research for acceptance, a thesis entitled **School Experiences of Successful Adults with Blindness** submitted by **Dianne Wynne McConnell** in partial fulfillment of the requirements for the degree of **Doctor of Philosophy** in **Special Education.**

Dr. R. Sobsey

Dr. L. McDonald

Peter Calder
Dr. P. Calder

Dr. E. C. Lechelt

Dr. L. Wilgosh

for Dr. S. M. Rogow

Date: June 24, 1997

TO MY DAD

(GEORGE W. GORDON)

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My family - Roy, Maren, Erik, Ben, and Marie
The Canadian National Institute for the Blind
Colleagues and friends

This poem reminds me of them.

Some People are Very Special

by Kristone

Some people have a wonderful way
Of putting others at ease ...
They say and do the little things
That will comfort and will please...
They have a special kind of warmth
They're quick to understand.
And whenever there is trouble
They lend a helping hand.
This world of ours is a better place
And happier by far ...
Because there are some special people
As wonderful as you are.

I deeply appreciate all of you.

ABSTRACT

The purpose of this study was to examine the school experiences of successful adults with blindness. The principles of hermeneutic phenomenlogy provided the methodology to determine how these adults experienced school and also the meaning of these school experiences. Six adults were interviewed during the study. I prepared for this research by doing an extensive literature review in the areas of needs of children with visual impairments, inclusion of children with significant visual impairments into regular education programs, development of identity, and successful transition into adulthood.

The interview transcripts were analyzed to determine common themes or structures of experience. As the co-researchers recalled their journey through their school career, they revealed the structures of their experiences. Data analysis revealed that the structures of experience consisted of polarizing forces that represented challenges of blindness and positive influencing forces. These polarizing forces were categorized within three major themes. Negative and positive feelings were associated with all three themes. The examples of these positive and negative feelings are discussed in a separate section following the discussion of theme three. The three themes revealed in this study were: (a) being disconnected versus being connected; (b) being unprepared versus being prepared; and (c) inhibiting behaviors and facilitating behaviors.

The co-researchers revealed the existence of two perspectives. The first perspective is that of the individuals' with sight who work in the field of visual impairment and blindness and concentrate on resources and perhaps educational tools. The second perspective is that of the students' with visual impairments or blindness. As I learned from my co-researchers, "there's no real status in being a perfect blind person." These

perspectives are important to the findings of this study because many of the negative challenges associated with blindness discussed throughout the results were associated with the first perspective. The insights of the co-researchers included information about early intervention, inclusion, opportunities for concept development and competition, rewards for work, dreaming the dream and having fun. These insights are generic in nature. This means that the structures of their experiences, or their insights, may pertain to other disabilities as well as vision loss. This study had a significant impact on my life.

The author suggests extensions of this study in the final chapter. These extensions include, the development of an assessment portfolio and establishing educational standards for the development of skills to manage blindness. I feel the voice of the participants in this study has the potential to benefit all special education programs.

TABLE OF CONTENTS

CHAPTER Page

I. NATURE OF THE INVESTIGATION 1
  Bracketing 3
    Personal Experience 4
    Experience and Training 4
  The Research Question 7
  Hermeneutic and Phenomenological Method of Inquiry 8
  The Rationale 9
  Significance of the Study 11
  Limitations of the Study 11

II. LITERATURE REVIEW 14
  Needs of Children with Visual Impairments 15
    Early Intervention 15
    Educational Needs 20
      Concept Development and Academic Needs 22
      Communciation Needs 23
      Social/Emotional Needs 24
      Orientation and Mobility Needs 26
      Daily Living Skills 26
      Career/Vocational Needs 27
    Equal Access to Information 28
      Teachers Lack of Experience 29
      Teaching Style 31
      Curriculum Materials 32
      Environmental Factors and Additional Support 33
    Parental and Community Needs 34
  Inclusion of Students with Visual Impairments into Regular Educational Placements 36
  Development of Self-Concept or Identity 43
    The Identity Project 44
    Identity Crisis 52
    Implications of Vision Loss in the Pursuit of Identity 54
  Successful Transition into Adulthood 56

III. METHOD 61
  Review of the Literature 61
  Co-researchers 61
  Validity and Reliability 64
    Internal Validity 65
    External Validity 66

Reliability . . . 67
Interviewing . . . 68
Method of Analysis . . . 71
The Hermeneutic Circle . . . 71
Data Analysis . . . 72
Method of Presentation of Findings . . . 73
Following the Study . . . 74
Ethical Concerns . . . 75

IV. RESULTS OF STUDY . . . 78
Review of Methods . . . 78
Data Analysis . . . 84
Findings of the Study . . . 86
Theme 1 - Being Disconnected versus The Need for Belonging . 90
Being Disconnected . . . 91
The Need for Belonging . . . 95
Theme 2 - Being Unprepared versus Being Prepared . . . 99
Being Unprepared . . . 100
Being prepared . . . 106
Theme 3 - Inhibiting Behaviors and Facilitating Behaviors . . . 109
Inhibiting behaviors . . . 110
Facilitating Behaviors . . . 115
Negative versus Positive Feelings . . . 120
Parents of Children with Visual Impairments . . . 121
Teachers . . . 124
Individuals with Blindness . . . 125
Parents of Children with Visual Impairments . . . 128
Teachers . . . 129
Individuals . . . 129
Conclusion . . . 130

V. DISCUSSION OF FINDINGS . . . 133
Significance of the Findings . . . 134
Application of the Findings . . . 140
Early Intervention . . . 141
Inclusion . . . 144
Opportunities for Concept Development and Competition . . . 151
Rewards for Work . . . 153
Dreaming the Dream . . . 154
Having Fun . . . 156
The Discovery . . . 159
As a Parent . . . 159
As a Teacher . . . 161
As a Consultant . . . 162
Conclusion . . . 163

BIBLIOGRAPHY 164
APPENDICES 170

APPENDICES

APPENDIX 1. GLOSSARY 170

APPENDIX 2. MATRIX 171

APPENDIX 3. LETTERS 172

APPENDIX 4. CONSENT FORM 175

APPENDIX 5. INTERVIEW GUIDE 176

APPENDIX 6. ETHICAL CONSIDERATIONS 177

APPENDIX 7. GUIDELINES 178

APPENDIX 8. REPORT CARD 180

APPENDIX 9. TEXT FROM BOOK 182

CHAPTER ONE

Nature of the Investigation

The purpose of this study was to examine the school experiences of adults with blindness. Qualitative research methods permitted the study of this issue in depth and detail because the field could be approached without being constrained by predetermined categories (Patton, 1990). Within the qualitative paradigm there are a number of methods used to approach research questions. How the questions are being asked and what the researcher intends to do with the data determine the qualitative method chosen.

For the purposes of this study, adults with blindness, who demonstrated management of their blindness as well as adjustment to blindness, were nominated as participants. Nominated participants who agreed to participate in this study became co-researchers. Some of these individuals felt successful. According to Tuttle (1984) success can be measured through some persons' sense of value and worth. He identified factors that contribute to high self-esteem, in order to capitalize on them, and analysed the factors that contribute to low self-esteem, in order to minimize their effects. Tuttle (1984) presented these factors as basic limitations which impact greatly on an individual life. He discussed these limitations in the following five areas: (a) implications for personal and home management; (b) implications for travel; (c) implications for reading and writing; (d) vocational implications; and (e) recreational implications. These factors affect self-esteem because they require a level of interdependence from persons with sight, to meet some of their needs even with the best adaptive behaviors and coping skills. Tuttle further expanded by making the statement, "the sighted find it easy to forget that interdependence is healthy and normal" (p. 19). He also reported that a source of self-esteem can be found in the prevailing attitudes and feelings about blindness held by others. How is this concept interpreted within the school environment where skills of blindness might be taught?

This study analysed the school experiences of successful adults with blindness. I was interested in examining the process of self-acceptance and the influences that the acquisition of appropriate skills may or may not have had during the process. Acquisition of appropriate skills may be an integral part in the development of positive self-concept or self-acceptance.

My interest and motivation for this research are grounded in my personal experiences with blindness. These personal experiences include parenting a child with blindness, teaching in a regular classroom and providing consulting services to educators and families who are involved with children who are blind. Aspects of these experiences have been incorporated into this study. My research will focus on childhood experiences with blindness within the school environment. I am interested in investigating the school experiences of individuals with blindness to determine a common phenomenon. I am highly motivated to make a contribution to the field of educating children with visual impairments and hope that my research will have some positive influence within the domain of educating children with visual impairments. As previously mentioned, this study incorporates my personal experiences with blindness. These experiences are discussed in the following section on bracketing.

Bracketing

As a qualitative researcher, I recognize the importance and necessity of analysing my position with respect to this topic. I have been working as a professional within the field of visual impairments and blindness for a number of years. As a result of my experiences, I have become an advocate for children with visual impairments. I have developed a philosophy regarding the supports that these children require within the educational environment. In an effort to strengthen the reliability of this study, I have bracketed my experiences with this topic in this section. I acknowledge the importance of approaching this research topic with a rich understanding of my biases in this field. I am prepared to approach this study with an open mind and accept the findings.

It is the responsibility of a qualitative researcher to attend to, and take ownership of personal subjective understandings. I am prepared to report any personal and professional information that may affect data collection, analysis and interpretation (either negatively or positively in the minds of users of the findings). As the researcher of this study, I recognize that I am the instrument in qualitative inquiry and therefore information must be included about personal connections, training and experiences that I bring to the field. I must answer questions such as, do I know the people, program, or topic studied (Patton, 1990)?

Personal Experience.

My area of interest is the education of children with blindness. I became interested in this field following the diagnosis of a very rare retinal disease in my two sons. My youngest son, who is presently 9 years old, underwent 31 eye operations and eventually had his eyes removed. This personal experience motivated me to go back to university and this resulted in a career change for me, from a classroom teacher to a vision consultant. I bring to this research project experience with blindness as a parent, a teacher, and a vision specialist.

Experience and Training.

As a parent, my initial experiences with blindness were neither pleasant or hopeful. These experiences included travelling with a sick baby, sitting in hospital waiting rooms or parent lounges, leaving a teaching career, fighting with my husband, trying to figure out how to communicate with physicians and organizing the care of my other children. I remember being hungry for information. My life felt very out of control and I was desperate for something to help me gain some control. Perhaps the following anecdote can provide some insight into my experiences with blindness at this time:

> My young son had several operations in Boston by this time. He was experiencing a tremendous amount of pain and therefore he was often not very settled. His brother and sister were running in a cross-country race on the other side of the city. Their team needed drivers and I was approached to drive. After a great deal of thought I decided that I would drive my children

and a few of their team mates. I had no one to care for my young son so I took him with us. We managed to arrive at the race without incident. During the race, he became increasing agitated. My anxiety began to increase. The races went on and by the time we were able to leave, I had a hysterical baby on my hands. Before we left, I tried to prepare the children for this situation by talking to them about what was happening. We also thought of some strategies that might be helpful in providing as much comfort as possible, to our screaming passenger. Unfortunately, none of our strategies worked and his behavior continued to escalate. When he becomes this agitated he starts getting sick and choking. I found this situation impossible. I pulled the van into a gas station parking lot and phoned my husband. I was crying and told him I was not getting back into the van, I could not drive these children home. He talked me down, told me to get into the van and get myself and the children home. I said, "okay."

As a classroom teacher, I did not experience children with blindness in my classroom or in my school. I did experience children with significant challenges in my classroom. I remember the feelings of anxiety I had at those times. I did not feel trained to provide an adequate program. I did not understand their needs. Many of these children required teaching assistant support. These were my first experiences working with a teaching assistant and I felt a great deal of stress about the situation. I certainly did not understand the working relationship between us. There were many,

many questions that I had about these children and there was no one to answer these questions for me.

My thoughts about the field of educating children with vision loss at this time include concerns about lack of materials and resources, lack of trained people to work with these children, and lack of understanding about the educational needs of this population of children. I believe that too many children with vision loss are integrated into classrooms where teachers do not have an awareness of the implications of blindness, do not have appropriate expectations from these children and have only limited resources and support to deal appropriately with the teaching of skills specific to blindness.

I believe that in order to have the opportunity to become successful adults, children with blindness require the acquisition of skills specific to their blindness and a positive healthy self-concept. Skills specific to blindness include: (a) braille reading and writing; (b) orientation and mobility (travel skills); (c) social skills; (d) self-help or daily living skills; and (e) use of assistive technology. I am wondering about several issues. How does the school environment influence the process of acquiring a positive self-image as a blind child? Are we appropriately facilitating the development of these skills? What is the experiential process of acquiring the necessary skills to support a successful adult lifestyle?

Tuttle (1984) reported that there is abundant evidence to support the conviction that children and adults with visual impairments can be capable, contributing members of their society. These individuals demonstrate competent skills of blindness and present as confident, self-fulfilled individuals, in other words, successful individuals.

To appropriately address the process of bracketing I collected information from two sources. Prior to interviewing my co-researchers I underwent an interview myself. The purpose of this initial interview was to revisit and record my previous experiences, personally and professionally. Throughout the project, I maintained a journal in which I recorded my reflections and insights with respect to the project.

The Research Question

For the purpose of this research project the hermeneutic phenomenological approach of inquiry best addressed what I wanted to do with the data collected. The hermeneutic phenomenological method offered the opportunity to describe the experience and further understand the meaning, attached to human behavior during life events, through interpretation of the experience. With an investigation of meaning, we are then able to understand the behaviors demonstrated within the context of the experience.

Hermeneutical phenomenological research asks two questions, 'How do individuals describe their experiences of something?' and 'What meaning does these experiences hold for them?' The first question is consistent with the question asked in a phenomenological study. The second question takes us deeper into the individual's experience where the researcher is able to interpret, with the co-researcher, what meaning an individual attributes to those experiences. The researcher begins to look at why the individuals had the experience they did. My experiences have provided me with the opportunity to meet very confident, successful blind adults. Did their experience within an integrated public school placement contribute to success as an adult? I believe that this success could have been influenced within the school environment and I am anxious to examine what form this influence may have taken. Therefore, the research question for this study is, "How did you experience school as a blind student and what did these experiences mean for you?"

Hermeneutic Phenomenological Method of Inquiry

Van Manen (1994) stated, "Phenomenology is, on one hand, description of the lived-through quality of lived experience, and on the other hand, description of meaning of the expressions of lived experience" (p. 25). According to Van Manen, when description is mediated by expression such as text, it contains a stronger element of interpretation.

A hermeneutic phenomenological study includes the pure description of an experience, but also includes the interpretation of that experience via the text in which the experience is offered. Thus, this study extended the reported and, therefore, personal nature of experience from individuals and included "meaning" of a specific experience. The inquiry must be descriptive in nature but also interpret the meaning of the experience. The purpose of hermeneutic phenomenological description and explanation is to achieve understanding through interpretation of the written description (Allan & Jensen, 1990). The researcher must critically examine the phenomenon in question, with the intention of gaining a deeper understanding of that phenomenon within the context that it has been offered.

The Rationale

Van Manen (1994) reported that the term "description" includes both the interpretive (hermeneutic) as well as the descriptive (phenomenological) elements. When he emphasizes the descriptive function, he uses the term phenomenology and hermeneutics when the interpretative function is emphasized. Van Manen reported that philosophers such as Silverman and strict followers of Husserl's transcendental method would insist that phenomenological research is purely descriptive and that interpretation falls outside the bounds of phenomenological research.

Modern hermeneutics are a theoretical approach that can inform qualitative inquiry. According to Patton (1990) hermeneutic philosophy, developed by Dilthey and other German philosophers in the 1800's, suggested that there are distinct principles by which we can guide interpretation, and therefore arrive at objective knowledge. Some philosophers believe hermeneutics should be viewed as an exploration of the nature of understanding, and suggest that within this view, objective knowledge is possible. Hermeneutic studies involve the process of moving an experience from an awareness of the experience, to a deeper knowledge of the inner mental life of humans and understanding of why they experienced the experience the way they did. According to Chessick (1990), Dilthey established that this process occurs by a method that he refers to as the hermeneutic circle. This process begins by asking the question and searching for its answers through participation and openness which perhaps may shake one's own belief. The researcher may ask for clarification and paraphrase interpretation. We perceive the world from our own particular time and place and the possibility exists that we can come to new understandings based on new experiences. Hermeneutical research requires researchers to be honest and open to altering our understanding and transforming preexisting meanings. The researcher must approach the research with the attitude that there will be a search for an understanding of self as well as an understanding of those being researched. Sharing an experience with someone is limited by the language said and recorded. Hermeneutical research therefore takes into account those things relevant to the phenomenon that are not said.

A hermeneutic phenomenological approach satisfies the discovery of the phenomenon experienced as a blind child at school. It also allows for interpretation of the experience through the context in which the experience occurred. A study by Allen and Jensen (1990) is a good example of how hermeneutic phenomenology can be used to effectively interpret the experiences of individuals with visual impairments. This study reported that at the early onset of blindness, meaning was one of loss and the behaviors associated were crying, drinking, or depression. It was through the interpretation of the meaning that we were able to understand the behavior. A hermeneutic phenomenological study has strong implications for the education of children with vision loss. Perhaps the results of a hermeneutic phenomenological study in this field would offer insights to educators about how they can facilitate the development of positive self-concept in children with blindness.

Significance of the Study

This study is significant for a number of reasons. The literature clearly indicates that the implications of visual impairment are not understood. Professionals working with individuals who are visually impaired are continually searching for faster and more efficient strategies to improve access to information. Visual impairment is an uncommon disability and therefore teachers, working with students who are visually impaired, are typically disadvantaged because they rarely have had previous experience teaching students who cannot access information visually. A negative result of this can be teachers with low expectations or limited expectations for these students. Throughout the literature there is representation of parents' perspectives, teachers' perspectives and other professional perspectives. Very little literature has been written representing the 'voice' of the student with visual impairment. This research, therefore, will allow teachers to gain some insight into teaching students with visual impairments from the voice of the student. This is possible because this study identified those positive and negative influences in the lives of the research participants. Perhaps gaining an understanding of these influences will improve educational services to students with visual impairments.

Limitations of the Study

One of the major limitations of this study stems from the fact that visual impairment is a low incidence disability. As a result, access to participants fitting the research criteria was limited. Research participants represent a fairly small geographical area. A second limitation to this study occurred as a result of investigating educational experiences from several years ago. Educational practices have changed drastically in a very short period of time, particularly with services to children with disabilities. It was important to understand the context within which the research participants' experiences took place. The description of schooling at this time was not totally familiar to me and therefore I had to gain some understanding of school experiences during this time. A third limitation to this study was the difficulty I had finding the words to adequately capture the passion of my experience with this project.

The findings of this study may have implications for parents, teachers and community members. It is therefore important for them to be able to understand the information that is discussed. Terminology specific to a field can create confusion and misinterpretation of the information. Throughout this study terminology specific to the field of visual impairment and blindness is used. This may present a fourth limitation to this study. To facilitate a better understanding of the material provided, a glossary of terms is available to the reader. This glossary is found in Appendix 1.

The research topic and its significance is introduced in chapter one. Chapter two presents the literature that was reviewed in order to provide the background necessary for me to appropriately participate during the interpretation of the participants' experiences. Understanding the context within which the experience occurred is an important part of understanding and interpreting what the experience means. Van Manen (1994) stated, "Lived experiences gather hermeneutic significance as we gather them by giving memory to them. Through mediation, conversations, day dreams, inspirations and to other interpretative acts we assign meaning to the phenomenon of lived life" (p. 37). Chapter three includes information about the selection of co-researchers of the study, how issues of credibility and trustworthiness will be addressed, and methods of inquiry. In chapter four and five, I will discuss the results of the data analysis and the findings of the study.

CHAPTER TWO

Literature Review

For the purposes of this study, information was gathered from: (a) The University of Alberta Library database; (b) The CNIB (Canadian National Institute for the Blind) National Library Services; (c)The Materials Resource Center, Northern Alberta, professional references section; and (d) The Internet.

To appropriately prepare myself for this study, I reviewed the literature in areas of: (a) needs of children with visual impairments; (b) inclusion or integration of children with visual impairments into regular education programs; (c) development of self-concept or identity; and (d) successful transition to adulthood. Much of this literature review focuses on literature addressing issues specific to children with visual impairments. Accessing literature about the needs of children with visual impairments was important to this study because the adults participating in this study were talking about their experiences as children. In order to fully understand these experiences I must understand the context of these experiences and the issues that the participants may have faced as children. The history of inclusive education issues provides the background necessary in understanding these experiences as they occurred in school. The literature addressing the development of identity during adolescence is significant to this study because the judgment of whether persons view themselves as successful or not depends on a positive self-concept (Tuttle, 1984). The process of developing a positive self-concept and factors that may influence this process are discussed. There is limited research available that discusses the views and perspectives of successful adults with visual impairments. The literature most closely relating to this topic is associated with employment issues. The findings of the literature review in these topic areas are discussed in this section.

Needs of Children with Visual Impairments

Blindness impacts on the lives of individuals and their significant others. The nature of the impact, the extent of the impact, and the source of the impact will vary depending on individual circumstance. Regardless of the circumstance, however, no one will disagree that blindness impinges upon or alters the lifestyle of an individual in meeting the practical, day-to-day demands of living. The needs of individuals with visual impairment are the same needs shared by all children. Although these needs are satisfied in the very same way, there are some needs that those with visual impairments meet by employing techniques and methods different from those of their sighted peers (Tuttle, 1984).

In order to gather information from the literature in this area, I designed a matrix that I used as an information gathering tool. The matrix has four categories under which relevant information was recorded as it appeared in the literature. These categories included: (a) early intervention; (b) educational needs; (c) equal access to information; and (d) needs of parents and community members. An example of this matrix appears in Appendix 2. The findings are discussed in the following sections.

Early Intervention

The incidence of birth disorders that result in blindness and deaf-blindness has increased in recent years. Sophisticated technological medical advances have enabled newborns with low birth weight and multiple disabilities to survive, thus increasing the population of blind, visually impaired and deaf-blind children (Trief, 1992). This has in turn sparked attention by early childhood development specialists. The underlying theme, in present literature by early developmental psychologists and educators, is that the learning process begins at birth for all infants. Ferrell (1986) reported that early education for children with a significant visual impairment continues to be premised on a belief that a visual impairment is primarily a problem of access to information that affects how something is learned, not what is learned.

Access to information is critical in the early life of a child with significant visual impairment. According to Ferrell (1986), the growing body of literature on neonatal development is indicating that newborns have much more sophisticated abilities than once thought. Ferrell's (1986) studies with babies indicated that they were once thought to have blurred vision. Now babies, 6 months old, are believed to have visual acuity equal to that of adults. Warrens' (1994) review of the literature revealed that there is enough evidence to support the conclusion that auditory and tactual perception in infants, with significant visual impairment, follows the same developmental course as for sighted infants. Both are good examples of how our knowledge about infants and very young children is changing.

The process in which children come to know and understand relationships in the external world, and between the world and themselves, is known as cognition. Vision is recognized as the principal contributor to the process of learning or cognition because it allows children to receive information about objects as a whole, at one time and at a distance. Vision also facilitates the ability to compare objects according to size, shape, color, and function. This process is much more difficult when we only have the other senses through which to provide the information. Research and practical experience indicates that it is possible to process this information by other sensory input (Scott, 1982). Early education programming, therefore, provides opportunities to learn in ways that circumvent visual impairments. A learning experience for a preschooler in an early intervention program might include the demonstration of the concept to the child, then doing it with the child, then having the child perform it alone, and finally having the child demonstrate the concept when requested. Using familiar objects and direct experiences enhances this process because the information is presented directly rather than abstractly. Thus children with significant vision loss would benefit from an early intervention program which provides experiences for them which they otherwise would not have. These experiences enhance concept development.

Trief (1992) offered a curriculum model to early intervention programs. The purpose of her curriculum is to provide ideas and strategies to stimulate and enhance the timely achievement of developmental milestones in early childhood. Her program provides ideas for specialized experiences to enhance concept development (premath, science, prereading and writing braille) which the children might not otherwise have.

Sighted infants and preschool children use vision to develop an understanding of the world around them and these visual experiences help them to internalize a body image, world image, their relationship in the external world, premath and science skills, and pre-reading and writing skills. As the child enters formal learning in a school setting, these earlier experiences form a reference base from which the child operates to build and expand his or her knowledge. Children whose reference base does not have a solid foundation of experience will fail to progress because they cannot build new concepts (Robinet, 1989). Preschoolers with a significant visual impairment have a better opportunity of developing this reference base if they have participated in early intervention programming that has been geared to developing concepts that children entering school are expected to know.

Ferrell (1986) reported that the field of early intervention programming for children with visual impairments has been active for many years but the body of literature to support it has been deficient. The research reflected problems that infants with visual impairments and their families face but there appeared to be little hard evidence that the rate and sequence of development in infants with visual impairments are any different from sighted infants. Recently, researchers studied play behaviors. Play is a major component of the first five or so years of most children's lives. Some professionals have described play as a child's business. Some believe that children come equipped with an intrinsic goal to engage in play and most embrace play with a mind-set similar to an adult work ethic (Skellenger & Hill, 1994). Through play a child acquires, practices, and adapts skills in all developmental areas (Linder, 1993). Involvement in play activities, especially more complex ones, does not come naturally to children with visual impairments (Skellenger & Hill, 1994).

Rettig (1994) suggested that children with visual impairments have deficits in play and these deficits are related to lags in several developmental domains. Vision loss leads to specific differences in play behavior of children who are visually impaired. For example, it has been found that when play behaviors of children with visual impairments are compared to their sighted peers: (a) they explore their surroundings and the objects in their surroundings less; (b) they frequently engage in solitary play that is repetitive and stereotyped as infant or preschooler; (c) they exhibit less spontaneous play; (d) they do not, or only rarely, imitate the routine activities of their caregivers; (e) they play less frequently with stuffed animals and dolls and rarely engage in animism; (f) they play less frequently with peers and usually direct their play toward adults; (g) they exhibit clear delays in the development of symbolic play and role play; and (h) they engage in play that contains fewer aggressive elements (Troster & Brambring, 1994).

Skellenger and Hill (1994), Rettig (1994), and Troster and Brambring (1994) have made contributions to early intervention programming through their recommendations of strategies and materials to minimize the limited access to experiences and information for preschoolers and infants. This body of literature supports the hypothesis that the developmental growth of children with visual impairments has typically been measured by standards developed for sighted children. The perception, therefore, of the link between visual impairments and developmental delay may rest in the comparison itself (Ferrell, 1986). Ferrell (1986) illustrated this point further when she stated, "the blind or visually handicapped child encounters numerous obstacles in the early years that may be overcome by specific intervention techniques or that simply might be, or ought to be, considered normal for visually handicapped children" (p. 129).

Information about early intervention programming is neither definitive nor complete. In the interim, it is clear that individuals working with preschool children with visual impairments should: (a) know the risks, know where the developmental problems have been documented, and understand why they might occur; (b) provide every possible learning opportunity to minimize those risks; and (c) set expectations for performance based on what is possible (Ferrell, 1986).

Educational Needs

It has been established that children with blindness or visual impairments have unique needs that require the acquisition of specialized skills in order for them to manage their blindness. These needs can be met in a variety of ways both inside and outside the school environment. Today, nearly 90 percent of blind and visually impaired students are in their local schools along with their sighted peers. They are travelling independently and will be working in jobs that previously were unavailable to visually impaired persons. The education and preparation they receive have much to do with this kind of progress. Since children spend a large majority of their time within a school environment, the educational perspective becomes an important part of our discussion.

Many researchers have established that children with visual impairments require special programming to meet needs created by blindness. The Alberta Education Guide for Teaching Students with Visual Impairments (1996) states,

> Students with visual impairments sometimes have fewer natural learning experiences. . . . Development of concepts is the basis for all learning. Spatial relationships, time, body awareness and self-awareness are just a few examples of fundamental concepts individuals need to make sense of their world. These concepts may need to be specifically taught to students with visual impairments. (p. VI.5)

Professionals within the California State Department of Education brought together parents, consumers, and leadership personnel from the field of education for children with visual impairments to identify needs of these children, which in turn facilitated the definition of service delivery. This initiative sparked national interest and as a result inspired the development of Program Planning and Evaluation for Blind and Visually Impaired Students: National Guidelines for Educational Excellence (Hazekamp & Huebner, 1989). This document defines National Educational Standards for programs teaching children with blindness and visual impairments. Unique educational needs are presented in this document under the following headings: (a) concept development and academic needs; (b) communication needs; (c) social/emotional needs; (d) sensory/motor needs; (e) orientation and mobility needs; (f) daily living skills; and (g) career/vocational needs.

Concept Development and Academic Needs. As discussed in the section on early intervention, visual impairment affects language development (Best, 1992). The sequence of language development may be the same as it is for sighted children but the transition between stages of development and the age at which development occurs may be different. Children with visual impairments may attach slightly different meanings to words. These meanings are based on their tactile and auditory experience of the words. Often their interpretation of words is considerably narrower than it would be for a sighted peer. For example, imagine how many cups 4-year-olds with sight would have had the opportunity to view. Their information would be based on colors, sizes, shapes, uses, materials, and context. Compare this with the tactile experiences of 4-year-olds with visual impairments. These experiences would be much more limited and therefore language development is affected (Best, 1992).

Children with visual impairments may have difficulty developing a good sense of body image (Hazekamp & Huebner, 1989). Concepts such as laterality, time, position, direction, size, shape, association, discrimination, sequence, quantity, sensations, emotions, actions, colors, matching, and classifying require teaching and therefore need to be included in planning an educational program. Warren (1994) reported that during the developmental process, children learn to recognize that members of a given conceptual class share some attributes in common. They also differ on other attributes and therefore alternate classifications are possible and important. In his summary, Warren stated that the development of mature thought requires adequate ability to deal with classification. When this information is interpreted within a school environment, it means that we must provide students with visual impairments with more information, more accurate information, more structured information and more time to assimilate information.

The developments of listening skills and study skills are important areas to include when the education program is planned. Listening can be a critical avenue of learning for students with visual impairments. This avenue is becoming more and more acessible to individuals with visual impairments because of the rapidly expanding technology for recording, indexing and compressing speech and for producing synthetic speech (Heinze, 1986). Research has shown that a high school student, who reads braille, may attain reading speeds of 90 words per minute or higher with good comprehension compared to 150-175 words per minute of recorded material. In some cases 275 words per minute using compressed speech maintaining good comprehension, have been documented (Heinze, 1986). Heinze (1986) made reference to several research studies (Bischoff, 1979; Hanninen, 1975; Hatlen, 1976) which indicated that students with visual impairments are not always efficient listeners and suggested that systematic training in this area is required.

Communication Needs. Communication skills are those skills that individuals with visual impairments need to develop to be independent in society. These skills should include: (a) listening skills through auditory training; (b) tactile discrimination, including braille skills; (c) skills in the use of electronic communication devices; (d) typing and handwriting skills; (e) knowledge of the experience with recording procedures; and (f) experience with a reader (Spungin, 1989). Rhyne (1981) stated that the primary step in the communication process, cognition, is similar for sighted and visually impaired students. They differ, however, in sensory input channels, background knowledge, social experiences and psychological makeup. For these reasons, intervention is required to ensure appropriate levels of development of communication skills.

Individuals with visual impairment require information about the nature of their vision loss and the implications of this loss. This information should be developed in such a way that individuals with vision loss are able to articulate this information to other individuals and identify their own needs as a result of this loss. The skill of informing others of individual needs and accessing support for those needs is known as self-advocacy (Hazekamp, 1986).

Social/Emotional Needs. Huebner (1986) reported findings of a study completed by La Greca and Mesibov (1979) which indicated that the quality of peer relationships developed by children with significant visual impairments was a significant factor contributing to their psychosocial adjustment. Factors to be considered that directly influenced peer relationships include acceptance, appearance, social skills, parental participation, and orientation and mobility (Scott, 1982). Scott (1982) stated that children with visual impairments will be in contact with children that have been influenced by prejudices and attitudes carried by their parents. The result of these attitudes is teasing and therefore it is important to prepare children with visual impairments to respond if these situations should occur (Scott, 1982). Appropriate responses in these situations may influence the development of a positive self-image but also place the individual on an equal playing field with his or her peers. Positive relationships have a better opportunity to develop if the players are on equal ground. Conformity is important to school-age children and therefore those who do not conform may stand out. Children with visual impairments are at risk because they do not have the visual information of how others present publicly. Presentation includes hair style, grooming, choice of clothing and the manner in which it is worn, mannerisms, posture, accessories and so on. Repetitive motor behaviors, such as body rocking, head swaying and eye rubbing are mannerisms which have frequently been associated with visual impairments. There are many factors that may cause these behaviors, e.g., lack of appropriate stimulation, and lack of information about what others are doing. Regardless of the cause of the behaviors, one must consider that their effects on others may include falsely believing that the child is developmentally delayed, autistic, or emotionally disturbed. Also the general public may label the child engaging in these behaviors as socially unacceptable. The effects on children who engage in these behaviors include: (a) being teased; (b) interference with children's ability to be a receptive learner; (c) increasing withdrawal; and (d) self-abusive behaviors or physical damage to self (Huebner, 1986). Social skills are learned in a number of ways. One is by observing. Parents and teachers can play an important role in the development of social skills by providing children with visual impairments information about how other people around them are interacting and modelling appropriate social interactions. Also, social contacts must be facilitated for children until they have learned how to do this for themselves. Orientation and mobility skills will be discussed in the next section.

Orientation and Mobility Needs. Lowenfeld (1981) reported that blindness imposes three basic limitations on individuals, (a) range and variety of concepts, (b) ability to get about, and (c) control of the environment and the self in relation to it. All three of these limitations are related to orientation and mobility (Hill, 1986). Orientation is defined as one's ability to cognitively map one's environment and understand how one's body relates to this environment. It is a process which involves the use of the senses to establish one's position and relationship to all other significant objects in one's environment. Mobility is defined as one's capacity, readiness and facility to move safely through this environment. Orientation and mobility skills are so closely related that in order to be efficient travelers, individuals must be proficient in both areas (Hill & Ponder, 1976). The ultimate goal of orientation and mobility instruction is to enable students to move purposefully in any environment, familiar or unfamiliar, and to function safely, gracefully, and independently. Students, who do not have the opportunity to travel independently within their schools and community, often lack fundamental information that is basic to sighted students. Lack of information can result in cognitive delays or the development of poor self-concept.

Daily Living Skills. Every day countless activities are performed which are essential to one's self-care and personal management. Skills which facilitate the participation in these activities and techniques of daily living or personal managements are known as daily living skills. Examples of these skills include caring for personal needs (toileting, hygiene, grooming, eating), process and routine of dressing and undressing, survival skills (time, money management, cooking, shopping, laundry), community skills (interpersonal, manners, eating out), and leisure or recreation skills (Spungin, 1981). Visual observation and incidental learning are not accessible avenues of learning for children with significant visual impairments. They are not able to observe movements, actions or manipulation of objects performed by others. If the children do not actively participate in these activities, in the home or school environment, they are at risk for becoming dependent individuals who lack the ability to perform routine tasks. Students with visual impairments should be observed in natural environments and an assessment of skill development in these areas should be made. A decision regarding whether or not the student receive instruction in the skill area or not should be based on whether or not the student completes the task: (a) safely; (b) with poise; (c) independently; (d) with confidence; and (e) in a traditional manner (Huebner, 1986).

Career/Vocational Needs. Career development, as a process, requires a unique approach to meet the individual needs of students with visual impairments. As children mature, they must assume the role as manager of their own personal system of career development. This process will be influenced by teachers, parents, and significant others beginning with the understanding that they believe individuals can be their own managers. It is important that those individuals involved clarify their perceptions, expectations, and contributions relative to the student (Simpson, 1986). A career development system consists of information, ideas, and opportunities. Students should have the opportunity to contact resource persons regarding career planning. This step is important because it allows the student to access information about skills necessary to perform within a certain career and provides the opportunity to actively explore and experience possible interests. When students get involved in community work placements, the community has an opportunity to become educated about the capabilities of individuals with blindness from a nonthreatening position. Career planning will be influenced by coping skills, life experiences, and spirit of adventure (Simpson, 1986).

Equal Access to Information

It was previously discussed, under educational needs, that individuals with vision loss must acquire specific skills to manage their blindness. These skills include braille reading and writing, an understanding of one's vision loss and the ability to articulate this information to the general public, age appropriate social skills, and self-help skills (Loumiet, Levack, & MaGee, 1993). Individuals with a significant vision loss also require access to information. Blindness creates limitations in the access of information for individuals with significant vision loss, at any age, and in most environments. The significance of facilitating equal access to information is discussed in this section.

A good curriculum defines what the student will learn and is delivered by individuals who are competent teachers. The sequence of teaching, derived from this knowledge, is then sequentially arranged into learning modules which are delivered to the student. The learner's progress is then measured against clearly defined sets of quantitative goals. The selection of materials and methodology flows from this process (Spungin, 1989).

If we assume that this process is a good one and most good teachers follow it, then it is important to note that this approach does not address adaptations for students who cannot access visual information presented in the learning modules. The issue becomes equal access to information. If one were to take into consideration the amount of material that is presented to a classroom on a daily basis, the implications for students who do not receive this information are significant. If students with visual impairments are to derive maximum benefit from the curriculum, their instruction must be soundly based in a multisensory approach directed toward the acquisition of information from other sources of sensory input to compensate, at least partially, for the reduced visual input (Hueber, De Lucci, Malone, & Olson, 1986). Within our educational system, it should be expected that information presented (teacher prepared, board work, overheads, bulletin board displays and so on) should be accessible to all students, regardless of a significant vision loss. Environmental factors should compliment the access to the information presented. Equal access to information is addressed in this section under the following headings, teachers' lack of experience, teaching style, curriculum materials, and environmental factors.

Teachers' Lack of Experience. Visual impairment is a low incidence disability. As a result, society holds limited information about vision loss and experiences with blind individuals are minimal. With limited contact, it is natural that expectations from these individuals could be low. Consequently, the blind child is rewarded for virtually any level of performance (Schroeder, 1993). According to Schroeder, even the best elements of society rarely hold more than tenuous and uncertain expectations for individuals with blindness. It is easy to understand, therefore, that children with blindness would lack a clear image of their own potential. For example, Schroeder's work addressed concerns within the blind community that children with blindness are not expected or do not have the opportunity to learn braille skills sufficient to support the proficient use of braille. His study referred to this concern as a braille literacy problem. He reported that today's braille literacy problem did not emerge from negative views on blindness but rather from a lack of any specific view, at all.

A possible consequence of teachers having no expectations or low expectations, from students with visual impairments, is that they may accept whatever their students produced. Research indicated that visual impairments evoked more awkwardness in people without disabilities, than any other disability (Hallahan & Kauffman, 1988). It has been suggested that this awkwardness has evolved from individuals' experiences with a person who is blind or from what they imagine blindness would be like for themselves. Resulting attitudes and beliefs influenced their relationships with persons who are blind (Scholl, 1986). For this reason, it is difficult for teachers to determine what to expect from children with visual impairments and to identify whether problems with behavior, tidiness, application, or concentration are as a result of the blindness or the absence of appropriate expectations. If an individual has not had the experience of teaching a child with a visual impairment, they have no way of measuring level of performance unless they have an understanding of what they can expect. This understanding could be influenced by a set of standards or information from a professional trained in the education of students with visual impairments. If teachers understand the implications of blindness and the importance of equal access, they can then recognize the significance of hands on experiences for students with visual impairments and hopefully incorporate more opportunities into their program (Best, 1992).

Teaching Style. Teaching style is an important consideration to be made when program planning for students with visual impairments. Best (1992) discussed PEGS on which to hang the various principles that are needed to cope with all aspects of teaching children with visual impairments. These PEGS, as he referred to them, included, position, presentation, experiences, expectations, giving information, and speed of working. A child's position in the school environment needs to be considered. Factors such as comfort for the child in different tasks, location of the desk in the classroom, lighting, windows and glare, placement and storage of materials (for example, are they easy to work with and get to), appropriate work surface, and legibility of braille or written materials are examples of position issues.

When presenting material, Best (1992) recommended that the teacher monitor quality of voice using the following criteria; (a) clear; (b) audible; (c) varied, and (d) pleasant. Descriptions need to be accurate with the use of appropriate vocabulary. Students with visual impairments have the right to access any material that their sighted peers have access to. Therefore teachers need to plan ahead and ensure that these same materials are accessible in alternate format if necessary. Further discussion of curriculum materials follows in the next section.

Curriculum Materials. Individuals with a vision loss are disadvantaged in our society when they do not have the ability or means to access visual information that is presented. Depending on the vision loss, equal access to information may involve transcribing regular print materials into braille or large print, facilitating access to maps and pictures by accessing models or real objects to accommodate tactile exploration, and preparing an auditory description of films and other visual aids that individuals have access to. These processes may be formidable tasks when one considers the volume of visual materials individuals have available to them on a daily basis.

Specialized technology has been developed to assist in the production of materials for use by individuals with vision loss. The pace of technological development has been rapid over the past few years, and one can expect that more and better tools and technologies lie ahead (Schreier, 1990). A host of new technology for individuals with vision loss is emerging. Advances in computer technology and electronics have the potential for giving individuals almost total access to the printed and electronic word (Todd, 1986). Parents and teachers must work cooperatively to identify and obtain all necessary resources. An example of a resource could be consultation from a teacher trained in the education of students with visual impairments. The consultant, school staff, and parents cooperatively determine the educational goals for the student and develop these goals into a working document. In light of reductions of supports at the school level, obtaining resources of this nature may not always be possible.

Individuals with visual impairments may therefore require specialized technical equipment to access information readily available to sighted students. Appropriate identification and utilization of resources will make a significant difference in the education of these individuals (Todd, 1986). Perceived needs specific to the use of assistive technology include access to qualified instructors, current technology and compatible equipment. Ongoing support and troubleshooting are also important in order to maximize the use of the equipment.

Environmental Factors and Additional Support. The delivery system of comprehensive special education services for children with visual impairments begin with the identification of children who may need specialized services. Assessment is an important part of this process because students' needs are determined by a variety of factors. For example, degree of vision loss, availability of specialized staff, programs offered within school and district, and experience of school staff may influence decisions about levels of professional support and program placement (Spungin, 1980). Students with visual impairment may require the involvement of professionals other than the classroom teacher. Professionals such as orientation and mobility instructors, braille instructors, rehabilitation teachers and specialized technicians may provide valuable input into the administration and delivery of a program designed to meet the needs of a child with visual impairment.

Parental and Community Needs

Parents and community members provide the support necessary for a child to grow and develop. For this reason the needs of children with visual impairments could not fully be discussed without an understanding of the needs of parents and community members who support children with visual impairments.

The first paragraph of the preface, written by Lowenfeld in Scott, Jan, and Freeman's (1985) book, Can't Your Child See?, opens with questions that are reported as most commonly asked by families with children who have been diagnosed as visually impaired. These questions include:

> What are children with little or no sight really like? Can they grow and develop like other children? Where do they go to school? Do blind people ever get married? Can they work and earn a living? Do they live in a world of darkness? Can they be happy? (p. ix)

These questions may reflect the overwhelming feeling that many parents experience when they face the prospect of parenting a child with visual impairment. These questions may also provide some insight for professionals about the kinds of information parents and community members may be lacking about the implications of visual impairments. A review of the literature revealed that common concerns about supporting children with visual impairments included the importance of contacting other parents (networking), safety, expectations, and mobility.

Testimony from parents indicated that it was important for them to participate in a support group for networking purposes and the positive influences that can occur.

Margie Wilson (1995) reported the following about her experience attending the National Federation of the Blind (NFB) National Convention:

> Throughout its literature the NFB repeats its conviction that it is respectable to be blind; that blindness is just one characteristic; and that when a person receives the proper training and opportunity, blindness can be reduced to the level of a mere nuisance, enabling him or her to compete on equal terms with the sighted. As parents of a blind child, we said that we believed this philosophy, but I'm not sure whether we really did or whether we just desperately hoped that it was true. The convention changed that. At the convention we saw that these beliefs are undeniable realities. (p. 37)

Also, if parents are in contact with one another, they have the opportunity to measure whether or not their child is developing along a normal continuum. Parents of sighted children have this opportunity on a daily basis.

Safety issues were another area that parents identified as a concern. Carol Castellano (1995) writes, in her letter to the Superintendent of Schools, "I am writing to explain our position on whether or not our daughter, Serena Cucco, can safely wait for me to pick her up at the bottom of the hill at Kings Road School" (p. 34). In this particular situation, the school created a policy to minimize Serena's independence in the best interest of her safety. Carol's concern is not for her daughter's safety but the school's perception of safety procedures which affected her daughter.

Scott et al., (1985) acknowledged that parents are concerned about what the future holds for a child with visual impairment. They responded to this concern with information about the positive changes that have occurred over the last 10 years. They reported that society has demonstrated a growing concern for its disadvantaged members but acknowledged a general lack of possibilities for individuals with visual impairments. This attitude directly correlates with expectations that people have of individuals with visual loss. For example, if people believe that completing a task without vision is impossible, they assume that the completion of that same task by an individual with vision loss is nothing short of miraculous. Lack of expectations in an educational and/or work placement can drastically influence the acquisition of normality for the individual who is blind. According to Scott et al., (1985), "There is no doubt that the greatest single obstacle with which blind people and their families must contend, and the one over which they have least control, is the attitude of the sighted public" (p. 219).

This section addressed the implications of blindness within the educational environment. As the participants of this study reveal their experiences within the educational environment it will be interesting to note if their testimony provides any consistencies and discrepancies with the information that has been presented.

The next section discusses issues of inclusion as they pertain to children with visual impairments.

Inclusion of Students with Visual Impairments into Regular Education Placements

Issues of inclusion are relevant to this study because, in the 1960's, children with significant vision loss were sent out of Alberta to attend schools for the children with blindness. The Alberta Society for the Visually Impaired (ASVI) was founded in

1971 by a group of parents of children with visual impairments. Their mandate was to lobby the government for funds to train professionals to provide educational supports so that children with visual impairments could remain in their homes while going to school. They were very successful and as a result children with significant visual impairments, living in Alberta, more than likely attend public school. Significant vision loss is a low incidence disability. For this reason my participant sample may include adults within a large age range. Some of these individuals may have attended schools for the blind, while others may have remained at home and attended public school. For those participants included in the public system, inclusion issues become relevant to the study and therefore are addressed in this section.

The purpose of education is to equip all children and youth with life competencies that enable them to love, to work, and to play within the context of an acceptable system of values (Tuttle, 1986). Although educators would generally agree with this statement, the interpretation for children with severe disabilities is challenging. Many children with disabilities are included in regular education programs and, as a result, many controversies have developed around the appropriateness of these placements. Before the issues surrounding inclusion are addressed, an understanding of the working definitions are important (Wilgosh, 1992). Some individuals, who advocate for inclusion, may interpret inclusion as the process of full integration. Full integration means that students must never be separated from the regular stream regardless of the learning objectives. Other advocates see inclusion as children with disabilities attending their neighborhood schools and receiving varying levels of support within the school. Support could mean the addition of a teaching assistant, specialized equipment or specialized services or therapy offered at the school level. Depending on whom you talk with, their perception of inclusion could be one of the above definitions or somewhere in between. This section reviews the literature and reports current inclusion issues that may affect students with visual impairments.

Children and youth with disabilities have unique needs that prevent the attainment of life competencies through ordinary provisions of general education. As stated previously, students with visual impairments require specialized skills to manage their blindness. These skills include braille reading and writing, travel skills, self-help skills and abilities to use specialized technology. Special education programs developed to address individual needs in the pursuit of attaining these competencies.

Stainback, Stainback, and Bunch (1989) have reported that general education in effect operates as a "dual system" of education. This "dual system" of education has special education and regular or general education operating side by side, each with their own pupils, teachers, supervisory staff, and funding system. The issues of inclusion challenge the proponents of the "dual system". Wilgosh (1992) reported that Alberta Education is beginning to acknowledge that children with disabilities should be removed from a regular program only when their need's are not being met. Return to the regular program should always be the primary goal of individual programming. Children with significant vision loss are often the only students in their school with significant vision loss. Specialized skills necessary to manage blindness may have to be taught in a segregated placement. Questions frequently asked by teachers include: (a)

When does this occur during the school day?; (b) How often should it occur?; and (c) Who will provide the instruction?. At this point, there are no clear directions regarding the response to these questions.

The Bill of Rights passed in 1958, made provision for specific rights to individuals within Canadian federal jurisdiction. Since then educational experiences of individuals with exceptional or disabling conditions have facilitated changes in educational policy and direction (Stewin & McCann, 1987). One dramatic change has been the development of educational programmes that facilitate "normalization".

Wolfensburger (cited in Hallahan & Kauffman, 1988) has popularized the belief that every person with a disability should have an educational and living environment as close to normal as possible. This philosophy has become associated with the term, "normalization". Many professionals have viewed mainstreaming, as the primary methods by which schools can help exceptional children achieve normalization (Hallahan & Kauffman, 1988). Mainstreaming is "the temporal, instructional, and social integration of eligible exceptional children with normal peers on an ongoing, individually determined educational planning and programming process" (Kauffman, Gottlieb, Agard, & Kukic, cited in Bailey & Wolery, 1984, p. 109). Mainstreaming has been used, by some individuals, synonymously with the term integration and more recently, inclusion. Flynn and Kowalczyk-McPhee (1989) define integration as something that has been made whole by uniting different parts.

Integration has resulted from an attempt to reduce the dichotomous effect of a dual system of education (Stainback et al., 1989). The reality of the situation is that, unless the school system has adopted the philosophy that these children really belong in a regular classroom and are therefore members of that classroom, they are still classified as special education students. Regular education for all is based on several assumptions about people and learning. First, each child has the right to belong and should be welcomed as a full member of his or her neighbourhood school. Secondly, each child has the right to grow and develop in relationships with peers who have diverse skills. A third assumption is that schools should strive to be communities that value diversity. A final assumption is that people need to dream and to express hopes for the future (Forest & Lusthaus, 1989).

Educating students in regular education is controversial because it raises deeply provocative educational and social issues (Forest & Lusthaus, 1989). The Provincial Executive Counsel of the Alberta Teachers Association resolved to develop and publicize a comprehensive position on, and strategies for dealing with, the combination of emerging trends in curriculum, methodology, and organization that are imposing unsound educational practices on teachers and creating conflicting and unreasonable expectations of public education (Committee on Public Education and Professional Counsel, 1993). This committee invited teachers, administrators, school representatives, local secretaries, and interested individuals to respond to several issues specific to recent trends and initiatives in education. One of these trends is integration. The submissions responding to integration issues expressed a deep concern that in too many cases the process is not working, and in fact creating educationally unsound situations. These responses cited problems with implementation, lack of necessary support, that it is a good idea for some but not for others, lack of essential training for "regular" teachers, lack of inservice training, impact of these practices on "regular" students, failure to meet the needs of either "special needs" or "regular" students, medical aspects, teachers in some "no win" situations, and, cost/benefit ratios, as reasons for these concerns. Although implementation of specialized technology is not specifically mentioned as one of these concerns, lack of training, support, and funds certainly influences the placement of this equipment into classrooms.

In the classroom, children with disabilities require modification of the typical school routine, program, or practices in order for them to have increased opportunity for successful development. The literature reveals that in order for an integrated placement to be successful, the teacher must make physical and cognitive adaptations to the already existing program (Bailey & Wolery, 1984). The teacher must make provisions for multisensory learning and experiences. The students' individual programs must consider their strengths and weaknesses as they relate to the curriculum. Also, the teacher must have adequate preparation and resource information to deliver a program addressing the needs of an exceptional child. If possible, the teacher should have access to a professional trained in the education of exceptional children and the school should have a support system established that the teacher can access (Bailey & Wolery, 1984).

The number of students with visual impairments is on the rise (Huebner, 1989). Materials Resource Center (MRC) literature indicated that over the past 10 years the number of students receiving service has increased from 145 to 357. Effective integration is dependent upon the severity of the disability, the age of the child, the developmental level of the child, the goals of the program and the training of the teacher (Bailey & Wolery, 1984). Based on the diversity of factors involved in the planning of an educational program, research must continue to address the issues of integration in order for educators to provide the best programming for students with a disabling condition.

Whether mainstreaming results in positive or negative outcomes for children with or without disabilities depends on how teachers structure classroom learning (Johnson & Johnson, 1989). How teachers structure their classrooms directly reflects the training and experiences that they have had and the philosophies that the school jurisdictions operate under. Institutions of higher education have the opportunities to lead the way in the preparation of a regular education system designed to meet the unique needs of all students. These institutes could teach prospective teachers how to facilitate the merger of general education and special education (Stainback et al., 1989).

The manners in which these inclusion issues were dealt with at the time the participants of this study attended their school may have influenced their experience. The nature of this influence will be examined during the analysis of the interview data.

The next section discusses in more detail how significant others can influence the development of self-concept for individuals with visual impairment.

Development of Self-Concept or Identity

The process by which young people identify themselves and grow beyond what they are has been described as the identity project (Mitchell, 1992). This project is labor intensive and requires work. It is not something that automatically occurs during the adolescent period of development. According to Mitchell, the nuclear ingredients of identity include: (a) a set of values and beliefs to guide one's occupational options; (b) intrinsic characteristics defined by identification with other people who are admired and who influence what the person should become and do, and by societal values to which a person is exposed while growing up in a particular country, community and subcultural group; and (c) consistencies which indicate to the adolescent that he or she is similar in some ways to most people, yet different in some ways from all people.

As stated previously, the identity project requires constant effort or work and is not something that automatically occurs. Many adolescents require ongoing support and guidance such as information, reinforcement, motivation, and creation of opportunities from adults to assist them with their projects. Some adolescents require spiritual guidance during their pursuit of self-definition. According to Mitchell (1992), if these adolescents do not receive this needed support, much of their identity project will be wasted, lost, amount to nothing, become negative, or self-destructive.

Societies do not remain passive participants as youth move through their identity projects if societies allow freedom for experimentation. At the same time they continue to maintain structure and discipline to protect vulnerable individuals from destructive influences. According to Mitchell (1992), the development of identity is an integral part of adolescence. The implications of supporting youth with significant vision losses are considerably greater than the support that is needed for an individual who is sighted. The purpose of this section is to expand on the concept of the development of identity, as presented by Mitchell, and develop an awareness of how this process is affected by significant vision loss. This section is important to this study because the participants experienced adolescence and developed a positive identity. Tuttle (1984) reported that a healthy self-esteem increases the likelihood of success.

This section is divided into three subsections. Subsection one looks closely at the nuclear ingredients of identity as they pertain to individuals with visual impairments. Excerpts from autobiographies by Tom Sullivan (1975) and Harry Cordellos (1981) are used to support relevant points. These individuals are blind and wrote about their experiences as adolescents with blindness. Subsection two defines identity crisis and discusses similarities and differences between the individuals with sight and individuals with blindness. The final subsection summarizes the implications of vision loss in the pursuit of identity.

The Identity Project

The first component of the nuclear ingredient of identity has been stated as, "the process of developing a set of values and beliefs to guide one's actions and at the same time establishing a set of career goals which help to formulate one's occupational options" (Mitchell, 1992). Tuttle (1984) reported that the values and beliefs one has about oneself formulate the individual's self-concept, and this self-concept is then instrumental in establishing career goals. He discussed the development of self-concept in individuals with visual impairments and stated, "an individual's perception of his world and its demands coupled with his perceptions of his own abilities to cope with those demands, are determinants of his behavior" (p. 62). The way people conceive of themselves will influence both what they choose to do and what their expectations from life will be. Their career choices are, therefore, limited to their perception of what they believe they are able to accomplish.

Typically, this perception of the relationship between self-concept and career choice holds true for the sighted as well as the visually impaired. However, adolescents with vision loss must rely on others for information about their environment and their relationship with it. Dependency on others fosters a lack of trust in their own judgments or perceptions about themselves (Tuttle, 1984). As the child with blindness becomes increasingly aware of the abilities of the sighted and the obvious inabilities therefore of himself/herself, he/she will naturally be curious and envious of the sighted (Cook-Clampert, 1961). The lack of trust coupled with a feeling of inferiority places adolescents with vision loss in danger of developing a poor self-concept.

Harry Cordellos (1981) spoke of this lack of trust in himself and others in the following excerpt:

> It was obvious that the only way I could eliminate getting into any trouble or dangerous situations were simply to eliminate the activities, so I attended none of them. On Senior Day I did go to the stadium as usual for lunch, and ended up watching the rest of the class have fun on the field below (p. 19).

Cordellos (1981) explained that his decision to watch rather than participate and risk drawing attention to himself, was a result of his lack of trust in his own judgments. Tom Sullivan (1975) recounted an incident where his roommate, in his first year of college, stopped him as he was leaving for a big date to say that his socks were on the wrong feet. Tom initially challenged this fact but had no way of disputing the contrary. This lack of trust in both of these situations resulted from the inability to conceptualize the world around them. As a result of vision loss, Harry and Tom were not able to grasp the concepts of the everyday habits and exchanges between their sighted peers. Tom did not know for certain that there were not, in fact, a right and left sock.

Research has indicated that blindness modifies some cognitive functions, which may have a retarding influence, which is most noticeable during early and preadolescence (Tuttle, 1984). Vision plays a dominant role in the conceptualisation process and therefore the individual with blindness must integrate information from other senses to develop or formulate the concept. The potential for blind persons to gain an understanding of people, objects, and events in their environment remains intact, however, they frequently lack repeated, first-hand experiences upon which to formulate and validate hypotheses about the world around them. Individuals with visual impairments are unable to immediately perceive alternative courses of action such as which door to enter an unfamiliar building. They are limited to the one that they first discover. Blindness can be limiting in this regard and, as a result, decisions may be made for individuals without consulting them. As a result, adolescents with visual impairments lack control over their environment.

Scenarios such as those described foster dependence on others for vital information and, as a result, the young, immature individuals with visual impairments tend to adopt the judgements or perceptions of significant others in preference to their own. The more dependent the individual, the more likely he/she is to accept without question the significant others' opinions regarding his attributes. Dependency on others interferes with self-sufficiency and autonomy, the drive to be on equal footing with others (Tuttle, 1984). The identity project may be at risk at this point if the significant other believes that an individual with visual loss is less capable than an individual with sight.

The abilities of a person with blindness are often underestimated by the general public because abilities are measured from a sighted vantage point. The general public typically relates to a person with blindness from a negative perspective. Tuttle (1984) compiled a list of stereotypic attitudes toward blindness. Some of these attitudes included: (a) inferior, helpless and useless; (b) pitiable, miserable, and wretched; (c) to be ridiculed for stupidity, impaired understanding and other generalized incapacities; (d) unapproachable with comfort or ease; and (e) living in constant darkness or blackness. These negative perceptions exist because vision loss is a low incidence disability and the general public does not have frequent and/or ongoing exposure to a person with vision loss, if they had any at all. Therefore, the opinions that are formulated result from: (a) influences from the media's portrayal of blindness (television, newspapers, magazines and movies); (b) the attribution and spread of phenomena which attribute all of one's problems to blindness; (c) commonly held public attitudes; (d) lack of expectations from the individuals with blindness; and (e) the manner in which the individuals with visual impairments present themselves (Tuttle, 1984). As discussed previously, the inherent danger for adolescents with visual impairments is that they are in a situation where they have more trust in the perceptions of the significant others than they do for themselves in defining their personal attributes. These persistent negative defining attributes from the significant others inevitably become the personal attributes of the individuals with visual impairments and potentially contribute to an identity crisis. Identity crisis will be discussed later in the section.

The individual's opportunity to develop intrinsic characteristics by identification with those people who are admired and who influence what the person should become and do, is the second ingredient of identity (Mitchell, 1992). Our society is rich with opportunities to discover positive role models. The media has facilitated contact with professional sports figures, entertainers, musicians and so on. The child with a visual disability must continuously interact with sighted persons in a world designed for the sighted. Access to positive role models is much more limiting and therefore he/she may be predisposed to view and rate himself/herself in terms of individuals with sight. Few adolescents with blindness have ever met or even heard of a successful blind or partially sighted person, so they have few opportunities, if any, to have contact and exposure to a role model (Scott, 1982). Social behaviours and attitudes are learned partly by observation and imitation. Vision loss limits the number, range, and variety of observations and restricts the opportunities for participating in social situations (Tuttle, 1984). As a result of this limited access to some successful role models, children who are blind, as well as their significant others, don't clearly know what to strive for.

Individuals with blindness can accomplish most of the same things sighted individuals can, but there are real limitations which accompany blindness that can restrict mobility and impede social relationships. These limitations may produce feelings of inferiority (Cook-Clampert, 1961). For example, assume that individuals with visual impairments have the same desire for independence as their sighted peers and they are not able to obtain it. In order for them to cope with travelling because they cannot drive a car, they are forced to depend on friends and family for transportation. Public transportation is an alternative, however, it is often inconvenient, and the routes may be limited. The ability to drive signifies freedom, status, and the key to societal success for adolescents. The car provides teenagers with a private place where they can talk and openly express their feelings for each other (Huebner, 1986). Potentially, individuals with visual impairments could feel inferior, sad, or resentful (Scott, 1982). They could become acutely aware of their difference through these experiences and therefore must have the opportunity to discuss their fears and anxieties.

Society's attitude may be oversolicitous or too lenient, and as a result, adolescents may receive the message that they are not expected to measure up to their sighted peers. Tom Sullivan (1975) recounts this story from his early adolescent years:

> It was easy to be the best of the blind. But being the best at Perkins gave me a false sense of superiority. At Perkins, for instance, we played a modified game of football. I was the star player. But with the gang in West Roxbury the kids would not let me run with the ball. Among my sighted friends the game revolved around

> me. Overcome by frustration and shame, I knew I was the worst player on the field. (p.40)

If individuals had any doubts about their own self-worth, it would be confirmed in a situation similar to the one mentioned above. Individuals with visual impairments need to be reassured that there are other students with visual impairments like themselves who are undergoing the same kinds of experiences. They must be informed about successful individuals with visual impairments (Scott, 1982). Parents and teachers need to search out and facilitate opportunities for teenagers who are visually disabled to meet high-functioning individuals with blindness (Mangold, 1983).

The final nuclear ingredient of identity includes those consistencies in the life of the individual which indicate that he or she is similar in some ways to most people, yet different in some ways from all people (Mitchell, 1992). “Continuity” is the term used to describe one's behaviour that is consistent, predictable, and persistent. Despite the everyday changes and demands in one's life, consistency accounts for the fact that individuals remain persistently themselves.

“Differentiation”, on the other hand, is the term used to describe the process by which the individual becomes different from others. One of the purposes of the identity project is to establish one's individuality. Experimentation with continuity and differentiation is tied into the peer experience, especially in our society where most teens with sight spend virtually all their social time in the presence of one another. Belonging to a referent group depends on the individual's ability to play the role defined by that group and to make a contribution of some sort toward the welfare of the group (Tuttle, 1984).

Membership in a group provides an individual with an arena to experiment with individuality.

Teens with impaired vision are frequently more socially isolated. They are not always able to choose their companions for conversation, often needing to wait to be spoken to first. In a group setting, these individuals frequently find it difficult to know when comments are directed to them (Tuttle, 1984). Gestures of individuality such as trendy haircuts, clothing, and surface symbols of subcultures are used as standards of measure which indicate the individual's statement toward being the same or different from his/her peers. Individuals with vision loss lack control in the decisions that are made because they are dependent on others for direction and consequently selection within these areas. The standard of measure indicating the sameness or the differences from subcultures do not apply to adolescents with visual impairments if they are not making the decisions.

Vision allows individuals to compare themselves with others, and as a result adjustments can be made immediately if they feel that they need to redirect or change a path. Without this ability to compare themselves to others these individuals run the risk of believing that their perceived flaws are one of a kind or are much more severe than everyone else’s. Adolescents with visual impairments may take literally, offhand remarks made by peers about physical characteristics. Mangold (1983) provided a good example of this point when she presented a conversation she had with five adolescent females in which it was determined that a classmate did not have breasts the size of watermelons. These females originally thought that this was true because they did not have enough vision to know that the comments were in jest. These comments may result in an unrealistic image about themselves and others that can foster a distorted view of the individuals around them. Preoccupation with this concept may lead to self-consciousness and a poor self-image (Mangold, 1983).

Huebner's (1986) discussions about dating revealed that dating an individual with vision loss is viewed as inferior and therefore peer pressure prevents sighted individuals from dating individuals with vision loss. As a result, adolescents with vision loss may personalize this and view themselves as inferior.

At an age when peer relations and dating become influential forces, it is important that individuals with vision loss do not adopt stereotypic behaviours such as rocking, eye pressing or poking, associated with vision loss. Sullivan (1975) recounted that when he was young his mother helped him avoid these habits that cause so many blind people to look awkward, behave in a socially inappropriate way, or to be unattractive. It is important that individuals with vision loss are instructed in appropriate grooming, eating, and other social behaviours.

Identity Crisis

Mitchell (1992) explains that although a precise, universal definition of identity crisis does not exist, the general usage of this term has come to mean, "a temporary condition in which the adolescent is tormented by doubt, shows regressions in behaviour, and struggles to make greater sense out of the basic identity question, Who am I?" (p.140). Typically, identity crises can follow several courses.

Baumeister (cited in Mitchell, 1992) described two possible courses that identity crisis could follow - identity deficit and identity conflict. An identity deficit refers to an inadequately defined self that is characterized by a lack of commitment to goals and values. Individuals with vision loss who have not been encouraged to explore their capabilities or who lack skills and strategies to address the blindness are at risk of an identity deficit. These individuals may develop a self-concept that is inadequately defined because their identity indirectly reflects the concept that others have of them.

Identity conflict refers to the conflict that an individual has between commitments and beliefs that pull opposing directions. Individuals experiencing identity conflict have high levels of anxiety because their loyalties are competing with one another (Mitchell, 1992). Sullivan (1975) reported the following incident, which is a good example of identity conflict:

> . . . spend the rest of my life weaving baskets or whatever. Who the hell said I could make it in the sighted world? You know damned well I can't. You know I haven't got a chance. Why was I born blind? Go on answer that one. It'd been better if I'd been born Mongolian or a village idiot . . . .You've tried to make me reach for the impossible. I'm blind, don't you understand that Bill? I'm blind! Blind! Blind! (p. 92)

Tom is struggling with his loyalties to (a) the expectations that Bill had of him in his placement at Providence, (b) his loyalties to the blind community that he left at Perkins, and (c) his loyalty to himself and his feelings that attending Providence was something that he really wanted to do. Without resolution, Tom runs the risk of swinging his loyalties back and forth between the experience of the blind man in the sighted community or the blind man in the blind community, and never really discovers what it is that he wants or where he belongs.

Tuttle (1984) stated that an individual cannot remain in a state of crisis or disequilibrium for an extended period of time. Within weeks some resolution must be found. A period of crisis is accompanied with anxiety, and if the level of anxiety is too overwhelming, the individual may abandon the search for identity by foreclosing on it. When individuals foreclose on their identity they attain an identity without experimentation, e.g., an occupation, or role is accepted without looking at any other alternatives. This can easily occur in individuals with vision loss if they do not experiment and diversify.

If the crisis and the symptoms associated with it are extended, the result is identity diffusion, the inability to attain a self-definition, or the failure to maintain themselves with any consistent style. Their personality becomes a mixture of depression, acting out and bewilderment. Commonly, these individuals experienced worthlessness and self-hatred (Mitchell, 1992).

Implications of Vision Loss in the Pursuit of Identity

Although many of the anxieties for sighted and blinded are the same, individuals with vision loss are at higher risk for periods of identity crisis because more situations induce anxiety among the blind (Cook-Clampert, 1961). For example, blindness generates egocentric attitudes and behaviours because of a preoccupation with the adjustment and coping problems precipitated by the blindness. It is possible that these individuals will become aware that they are not mastering skills usually mastered by younger children. Blindness precipitates anxiety about the future if these individuals do not receive information about career choices and living options available to them. They do not automatically assume that they will live on their own and support a family as do their sighted peers.

Tobin and Hill (1988) surveyed 120 adolescents with visual impairments, 16-18 years of age. The purpose of the survey was to determine ambitions and attitudes. He discovered that, without prior knowledge of the respondents' disability, it would not be possible to infer from what they said that they were noticeably different from teenagers in general.

The most significant mitigating factor in the pursuit of identity for individuals with vision loss is that they receive support specific to their blindness. They should be able to disclose the reason(s) for their blindness and discuss the implications of it. They must develop advocacy skills that facilitate the establishment of age appropriate expectations within the general public. They must be able to accurately identify what their needs are specifically to equal access to information, and have the skills and strategies to access this information. In essence, one of the most important things that society can do as a whole is to facilitate the development of individuals who know how to be blind. This sets the playing field for individuals to maintain their sense of continuity and facilitates the security to explore differentiation.

Adolescents with visual impairments typically are as capable as their sighted peers in reaching identity achievement. Cordellos (1981) demonstrated achieved identity with the following quotation taken from the front page of his book, "When we can accept ourselves as we are and not be concerned about those things we may lack and when we can face each new challenge with faith, determination, and confidence, no obstacle is impossible to overcome."

Participants, for this study, were chosen because of their success in adulthood. Tuttle (1984) reported that, in order to make decisions which leads to successful lifestyles, individuals must have a positive self-concept. This section discussed how a positive self-concept or identity is developed and the role that significant others play in this process. This information will be helpful as the data from the interviews are analysed.

The final section of this chapter reports the findings of the literature review addressing transition into adulthood. The literature is lacking good research studies on the topic of how adults with blindness view success. Most studies address adult perspectives about employment.

Successful Transition into Adulthood

The purpose of this section is to examine the literature for information which allows us to better understand the meaning of success for adults. This information is presented from two perspectives, (a) the educational perspective, and (b) the personal perspective. According to Simpson (1986) the educational system has a responsibility to prepare youth for personal, social, community, and vocational adjustment in adulthood. These milestones are relevant to both blind and sighted populations. The educational system is teaching youth that in order to be successful these milestones must be reached.

Hamilton (1989) reported that in mainstreamed schools specific problems can arise for students with a significant vision loss as they approach transition into post-secondary training or placement in the work force. For example, students with significant visual impairments may not be aware of what adults with significant visual impairments are doing successfully in the labour force. The school system may not be aware of what adaptive technology is available to facilitate success in the work force or what potential funding sources exist. Without this information, students with significant vision loss may not receive adequate career counselling.

Johnson's (1995) study explored relationships among individual employees' levels of vision with, education and trust, resource sharing, and empowerment in work relationships. This study revealed that when employees felt a sense of control over the outcomes for which they are accountable, their performance improved. Johnson reported that employees with higher levels of education gave and received trust and resources, saw their interactions and relationships as empowering, and were seen as empowered by others. The author expressed that individuals with blindness may be stigmatized when they attempt to obtain competitive employment. Higher levels of education may assist persons with blindness to feel that are as capable as anyone else. Therefore, the results of this study strongly suggest that where ever possible, individuals with significant vision loss should be counselled toward higher education.

Personal awareness includes the understanding that appearance, hygiene, personal mannerisms, and behaviors contribute to perceptions of the person by others. Social and community goals include the acquisition of skills that facilitates their participation as effective members of a group, requires money management, and requires the use of community resources. Successful individuals must demonstrate a degree of independence by shopping for themselves and travelling without a guide. Vocational adjustments include the acquisition of skills, work ethic, and habits that facilitate employment in a work setting.

The literature revealed that in addition to the educational perspective of transition into adulthood there are also personal perspectives which need to be considered. First, transition into adulthood is not an isolated event. Rather, it is a series of events occurring over time. Each individual approaches these events and feelings in a unique way depending on self-concept, coping skills, and the spirit of adventure (Simpson, 1986). According to Tuttle (1984) self-awareness progresses as the individual identifies personal goals, personal values, and lifestyles. Successes are experienced when individuals with visual impairments evaluate their performance and recognize that they have attained or exceeded expectations. Choosing the appropriate expectation depends on an individual's self-concept or level of confidence to set a goal that is not too low. Children and adolescents who are visually impaired need to be faced with tasks commensurate with their abilities but also challenging enough to present a risk. With success they become self-motivated and gain the confidence needed for transition to adulthood (Simpson, 1986).

Page (1987) reported that, at the base of a blind person's struggle for self-actualization, is a continuing need to affirm oneself against the hard wall of prejudice that is so much a part of the life of individuals' with visual impairments. He goes further, explaining that within this prejudice lies the lowest of expectations of the abilities of individuals with vision loss. As a result they may never be challenged or find out what they could do if they took risks. People with blindness need to learn alternative skills and strategies to manage their blindness (Page, 1987).

Page and Cole (1987) have written about growing up blind. They stated that the future is very uncertain for any young person and it is especially uncertain for young persons with blindness. The purpose of their article is to stress the importance of the need for youth with blindness to know that adults with blindness do become successful. The National Federation of the Blind (NFB) acknowledged the importance of this statement when they developed their program, The March on Washington. This program provides the context in which adults with blindness act as role models for youth with blindness. Each year in February, the NFB organizes a March on Washington. More than 200 persons from 35-40 states gather in the capital for several days to visit members of congress. They speak with them about issues of importance to NFB members. Young delegates are partnered with an experienced delegate, thus providing the context for positive role modelling. The significance of a positive role model was discussed in the section on identity formatting.

Transition into adulthood is influenced by the educational system and the significant others that become involved in the lives of individuals with significant vision loss. According to the testimonies of Page and Cole (1987), success as a blind adult means building a sound understanding of what it means to live as an individual with blindness. These individuals need skills to access the sighted world. They need a good understanding of their own capabilities and the confidence to take risks.

This chapter discussed the needs of children with visual impairments and included, early intervention, educational needs, equal access to information, inclusion, development of identity and transition into adulthood. This information provided the background necessary to prepare for this study. Chapter three will discuss the process and criteria used for the selection of co-researchers for this study. Issues of credibility (validity) and reliability (trustworthiness) are also addressed. Finally, the method of inquiry will be outlined in detail and the collection and management of data will be explained.

CHAPTER THREE

Method

The purpose of this study is twofold: (a) to capture the phenomenon of attending school as a student without sight; and (b) to gain an understanding of the meaning of the experiences of the co-researchers. This section has been divided into three sections. The first section includes, a review of the literature, the process of selecting co-researchers, and the criteria developed for selection purposes. The second section addresses issues of credibility and trustworthiness (validity and reliability). The final section of this chapter presents information about the method of inquiry and the management of data. The hermeneutic circle is a subsection under method of inquiry.

Review of the literature

This study began with an extensive review of the literature. The literature reviewed was primarily specific to education of students with visual impairments and the process of developing identity or self-concept. However, to ensure that all relevant issues were addressed, literature reporting on inclusion issues and successful transition into adulthood were also accessed. This information prepared the researcher by providing some insight into the context that may surround the co-researchers experiences. Preparation of the researcher strengthens the credibility of this study.

Co-researchers

Co-researchers required for this study include adults with blindness who met the criteria discussed in this section. These individuals must have experienced some portion, if not all of their schooling as a student with blindness. The selection of suitable co-researchers followed a process referred to as purposive sampling. This was accomplished by setting out criteria which fit the needs of the study and looking for co-researchers that met the criteria (Patton, 1990).

The criteria for the selection of participants were developed from the literature on successful transition into adulthood and Tuttle's (1984) work in the area of success and self-concept. Based on these criteria, participants in this study were successful adults with blindness. The educational perspective defined successful adults as individuals who demonstrate personal, social, community, and vocational adjustment. A personal perspective as outlined by Page and Cole (1987) and Tuttle (1984) suggested that successful adults demonstrate a solid identity with the blind world. As a result they have developed skills that provide them with the ability to access information from the sighted world. The following criteria will be used in the selection of co-researchers:

- Personal adjustments - demonstrated ability to manage daily living skills and skills associated with routine home chores;
- Community adjustments - demonstrated ability to travel through one's physical environment safely;
- Vocational adjustments - demonstrated ability within a vocation;
- Social adjustments - demonstrated ability in a variety of recreational activities or hobbies;
- Specialized skills - demonstrated competence in reading and writing

> skills which provide them equal access to information commensurate with sighted peers.

The selection process began when the researcher contacted the president of the Alberta Society for the Visually Impaired (ASVI), and the executive director of the Canadian National Institute for the Blind (CNIB). Contact was made by letter. The letter contained information about the research study and the need for volunteers as co-researchers. The criteria that they would use for selection were outlined. A request was made for these groups to nominate suitable candidates, contact the nominees and provide them with information about the study. If the nominees were interested in participating, they were instructed to contact me within one week or give permission for the CNIB and ASVI to give me their names to allow me to make the contact. The CNIB and ASVI were provided with my phone number and address. A copy of the letter has been included in Appendix 3.

Once phone contact had been established with the potential co-researchers a meeting, with each of them, was scheduled. The purpose of this meeting was to: (a) review the information about the study; (b) discuss the criteria for co-researchers; (c) confirm their interest; and (d) address issues of confidentiality. This meeting took place at the homes of the co-researchers. Co-researchers participating in the study signed a consent form, included in Appendix 4.

All individuals contacted for this study were interested in participating and matched the criteria. If, for any reason, the potential co-researchers had not matched the criteria or were not interested in participating, they would have been thanked for their time. Care would have been taken to minimize discomfort, disappointment or uncomfortable feelings for these individuals. Attention would have been paid to the way in which this information was discussed (tone of voice, environment, genuine comments).

Validity and Reliability

The applied nature of qualitative inquiry makes it imperative that researchers and others are able to trust the results of the research and to feel confident that the study is reliable and valid (Merriam, 1988). Validity and reliability within qualitative research depend on methodological skill, sensitivity, and integrity of the researcher. A qualitative researcher requires discipline, knowledge, training, practice, creativity and a strong work ethic to generate useful and credible qualitative findings from observation, interviewing, and content analysis (Patton, 1990). According to Merriam (1988) theorists such as Lincoln and Guba argue that qualitative research is based on different assumptions about reality and therefore should have different conceptualizations of validity and reliability. Terms such as credibility and trustworthiness appear in the literature in discussions of validity and reliability. Lincoln and Guba (1985) proposed using the terms truth value for internal validity, transferability for external validity, and consistency for reliability. These three areas of concern will be addressed in the following sections.

Internal Validity.

Internal validity is achieved when the researcher's findings match reality. In other words, internal validity in qualitative research has to do with description and explanation, and whether or not a given explanation fits a given description (Janesick, 1994). A qualitative researcher may ask, "Is my explanation credible?" The qualitative researcher studies how people understand the world which means that "reality is understood as multiple sets of mental constructions . . . made by humans" (Lincoln and Guba, 1985, p. 296). Judging validity or truth of a study involves the researcher showing, "that he or she has represented those multiple constructions adequately, that is, that the reconstructions that have been arrived at via the inquiries are credible to the constructors of the original multiple realities." According to Merriam (1988), this can be accomplished if the researcher presents an honest account of how co-researchers view themselves and their experiences. Merriam presented six strategies for ensuring internal validity. This study incorporated four of the strategies, which included triangulation, member checks, peer examinations, and addressing the researcher's biases.

Triangulation incorporated data collection from multiple sources to confirm the emerging findings. For the purposes of this study, data was collected: (a) from the participants during the interview process; (b) from notes collected in a personal journal; and (c) from samples of writing from the co-researchers. These samples provided support and further insight into the experiences that they shared.

Member checks involved taking the data and the interpretations back to the participants and asking them if the results were plausible. This occurred continuously throughout the study. For the purposes of this study, co-researchers were invited to meet with the researcher following the process of data analysis.

The intended audience for this study is professionals and parents of children with visual impairments. Research methods are described in great detail. The discussion includes quotations, from co-researchers, taken from the interview data. Quotations validated the material presented. The uses of quotations in written documents was discussed with the co-researchers prior to the interview. Participants were comfortable and provided permission for their quotations to appear with personal details, such as their names. Information about the emerging themes was discussed with co-researchers to validate the data. When the findings were written, a copy was sent to the co-researchers for verification and feedback. Special attention was given to provide co-researchers with materials in alternate format (for example braille or tape) as required.

Peer examination occurred when the researcher met regularly with a skilled supervisory committee and discussed the study as it evolved. The researcher's biases were addressed in the section on bracketing.

External Validity.

External validity is concerned about how generalizable the results of the study are (Merriam, 1988). According to Merriam the question one might ask when testing for external validity is: "To what extent can the findings of this study be applied to other situations?" In the traditional sense, external validity cannot be applied to qualitative research because generalizing to other settings or people depends on standard sampling procedures. Instead, reader or user generalizability involves leaving the extent to which a study's findings apply to other situations up to the people in those situations. To provide the appropriate context from which they make this decision depends on how well the researcher has described the experience. A rich, thick description provides the information to make this judgment.

Reliability.

Reliability refers to the extent to which one's findings can be replicated (Merriam, 1988). This concept may pose problems for qualitative researchers if the working assumption is that qualitative research studies are reflections of individual realities and therefore cannot be replicated. Researchers such as Lincoln and Guba (1985) proposed that reliability could involve thinking about dependability and consistency of the results obtained from the data. Merriam (1988) suggested an audit trail account for detailed description and step by step analysis of the research procedures and methods. Janesick (1994) proposed that rigorous techniques and methods for gathering high-quality data that is carefully analysed, the credibility of the researcher, and a philosophical belief in the phenomenological paradigm, also contributes to the reliability of the research. The credibility of the researcher, in this study, began with the process of bracketing and the discussion of philosophical belief in the phenomenological paradigm, in chapter one.

Interviewing

Data was collected from three sources during this study. These were interviews, personal journal notes, and co-researcher's samples of writing. This section will address the principles guiding good interview techniques. An interview schedule was developed, taking into consideration the following five points:

- Development of a handout for each participant which addressed the purposes and procedures of the study;
- Development of a consent form that was signed prior to the interview. Participants required alternate format to access the information on the consent form;
- Development of the interview questions with consideration to the content of questions;
- Decisions about how I created a comfortable atmosphere which facilitated the development of good rapport between the participant and the researcher; and
- Development of an interview kit with all technical equipment and supplies, including contingency plans, necessary to appropriately record the data.

The procedures for the study, consent form, and interview questions have been included in Appendices 3, 4 and 5 respectively. The procedures for the study are outlined in the letter to CNIB and ASVI.

The interview consisted of open-ended questions in order to allow for a wide range of responses and to encourage the expression of personal views (Koole, 1983).

The interviews were tape-recorded so that I was able to pay full attention to the conversation and the co-researchers. Most tapes were transcribed by the researcher following the interviews. Those interviews that I was unable to transcribe, due to time considerations, were transcribed by a secretary. Prior to making this decision, I accessed permission from those co-researchers involved.

In order to create a comfortable interview environment, attention was given to the location, and attentiveness of the researcher. A conscious effort was made to be non-evaluative and not make criticisms about views that were expressed.

The following considerations contributed to the validity of the study: (a) number of interviews necessary to saturate the topic; (b) where and when to interview to facilitate optimal comfort; (c) length of interviews; (d) techniques for probing; (e) allowing for sufficient time; (f) providing co-researchers with questions ahead of time; and (g) quality of equipment used to record data. A skilled interviewer reviewed the data of the first interview and provided feedback to improve interviewing techniques for the subsequent interviews.

Co-researchers were interviewed individually, for a period of approximately one to two hours. During the interview they were asked questions about their experiences as a student with blindness. Questions were associated with focus areas. The focus areas included personal demographics, school related stories, experiences with friends and peers, management of blindness (for example, travel and access to information), extracurricular activities, and relationships with adults. Co-researchers were provided with information outlining the focus areas prior to the interview. They were informed that a second interview might be required if it became evident that I did not collect enough information from the first interview. This was determined at the end of the first interview. Following the data analysis I meet with participants to review the research findings. I was looking for verification that their experiences were correctly captured. Based on the participants' feedback during this meeting, I made some adjustments or corrections to the research data.

Issues regarding confidentiality were discussed with participants. I asked them whether or not they wanted a pen name to be used and if so, would they like to choose the pen name. All of the co-researchers chose to have their names used in the study. They were told that the interviews would be taped and that the tapes would be stored at my home office in a locked box. Most tapes were transcribed by me and this information is stored in my home office. I hired a secretary to transcribe those interviews that I was unable to do. Those co-researchers involved granted their permission for this to occur. Several copies of the printed information were produced. The tapes and transcribed information will be stored following the research project for several years.

I began this study by interviewing six adults. I recognized that this study may require more co-researchers depending on the richness of the data collected. The intent of this researcher was to continue to interview subjects until the topic became saturated, in other words, until the data collection no longer revealed new information (Morse, 1994). Upon completion of data collection the process of analysing the data began.

Method of Analysis

In phenonmenological research, participants in the study are often referred to as co-researchers in order to emphasize the cooperative and voluntary nature of the research (Osborne, 1990). The nature of the inquiry required an openness on the part of the co-researchers to share their experiences with the researcher. The researcher and co-researchers began a process wherein the researcher attempted to enter into the co-researchers' worlds with the goal of illuminating the phenomenon being investigated. Hermeneutic inquiry permitted the researcher to clarify and paraphrase the information received in an effort to interpret the phenomenon. This process has been established as a method of inquiry known as the hermeneutic circle (Chessick, 1990).

The Hermeneutic Circle An important part of the data analysis occurred at the time of the interview as the researcher and interviewee engaged in a dialectical exchange in an attempt to clarify the meaning of the experience. The interviewee assisted the researcher in the acquisition of information that accounted for the behaviors demonstrated at the time of the participant's experience. This process is known as the hermeneutic circle.

The hermeneutic circle is the process of moving back and forth between that which is known (the experience represented by the text) and the local details found in the text (underlying conditions, historically and aesthetically, that account for the experience). This process involved three steps:

a. The researcher clears her mind of priori assumptions and examines the text (for the purposes of this study the texts will be the transcriptions of the interviews). Thus having set aside prior explanations of the phenomena, the investigator can begin to understand the subjective meaning of the acts from the perspective of the participants. Empathy is used in order to illuminate the participants' meaning.

b. The interpretation begins with successive readings of the text. Through a spiralling process, the researcher considers newly illuminated aspects of the text, challenging them, and revising his or her understanding (Klassen, 1995). This process refines the interpretations, making them increasingly valid.

c. The findings are conveyed accurately and clearly through language.

The hermeneutic circle examined the contextual nature of the experience and therefore texts that were unclear or were prone to misinterpretation were made clear. As this study was interested in understanding the influences of the school environment for the participants, it is apparent that the understanding of the context within which the experience occurred was a critical factor in the analysis of the data.

Data Analysis

The text developed from each interview was analysed following the principles of thematic analysis as outlined by van Manen (1994). Theme analysis refers to the process of recovering the theme or themes that are embodied and dramatized in the evolving meanings and imagery of the work. According to van Manen, theme gives control and order to our research and writing. Van Manen described a theme as: (a) the experience of focus, of meaning, of points; (b) a simplification; (c) themes are not objects one encounters at certain points or moments in the text; and (d) form of capturing the phenomenon one tries to understand. Thematic analysis can take three approaches toward uncovering or isolating thematic aspects of a phenomenon in some text. These approaches include holistic or sententious approach, selective or highlighting approach, or the detailed line-by-line approach. In the holistic approach the researcher would attend to the text as a whole and ask, "What is the sententious phrase that will capture the fundamental meaning or main significance of the text as a whole?" In the selective or highlighting approach the researcher listens or reads a text several times and asks, "What statement(s) or phrase(s) seem particularly essential or revealing about the phenomenon or experience being described?" Finally, the line-by-line approach requires the researcher to look at every line and ask, "What does this line reveal about the phenomenon?" For the purposes of this study, the principles of the line-by-line interpretation were adhered to. In an effort to manage the data, the transcriptions were prepared on the left-hand side of the paper. The right-hand side of the paper was therefore free in order to allow room for the process of analysing to occur. During this process the researcher looked specifically for words, phrases or feelings that could be grouped together to form categories or themes.

The journal notes and personal work samples collected were used to confirm, support, and challenge emerging themes. This information was documented as part of the audit trail. The research findings were returned to the co-researchers for verification.

Method of Presentation of Findings

There are several audiences that I will inform about the results of this study. The Canadian National Institute for the Blind (CNIB) provides many opportunities for speakers to share research information. Individuals associated with the CNIB include clients, their families and professionals working with children who have visual impairments. The Alberta Society for the Visually Impaired (ASVI) is a parent support group which is very active in the field. I was president of this organization last year and it is my hope that they would welcome the opportunity to have me present information from this study to their organization. I would like to prepare an article which summarizes the findings of my study for submission to professional journals such as Journal of Visual Impairment and Blindness or Exceptional Children. Finally, I would look for opportunities to present these findings at poster and conference sessions and workshops for the educational community.

Following the study.

Teachers are supportive of research material that generalizes to their teaching situation. As a consultant for the visually impaired, I have had the opportunity to work with many teachers. These teachers required information about working with students who have visual impairments because of a limited literature base and no previous experiences with visual impairments. My study highlights the voice of the student with visual impairments and therefore provides the teacher with valuable insights about those strategies or supports that made a difference.

Ethical Concerns

Qualitative research is highly personal and interpersonal because naturalistic inquiries take the researcher into the world where people live and work. In-depth interviewing opens up what is inside people, and as a result, it may be more intrusive and involve greater reactivity than surveys, tests, and other quantitative approaches. According to Bogdan & Biklen (1992), two issues dominate recent guidelines of ethics in research with human subjects. These include informed consent and the protection of subjects from harm. Guidelines have been established around these issues to ensure that participants enter research projects voluntarily, understand the nature and obligations of the study, and are not exposed to more risk than gain. Subjects understood that they could withdraw from the study at any time and that data would not be used for the study without their permission. These guidelines were provided to the participants on a consent form that was discussed with them. The participant's signature on the form is evidence that consent has been granted. My study involved individuals with visual impairments and therefore considerations were made to provide alternate format to provide access to the information on the consent form. For example, individuals were braille users and therefore the form was brailled.

Patton (1990) suggested that research within the qualitative paradigm requires consideration of many ethical issues. Interviews can become confessions, particularly under the promise of confidentiality, and they may open old wounds. Preparation for these situations requires the researcher to carry a list of counselling or referral services that interviewees may access if necessary. Participants in this study were advised to contact the Alberta Society for the Visually Impaired (ASVI) or the CNIB. A comprehensive list outlining Patton's remaining ethical considerations is included in Appendix 6.

Van Manen's (1994) discussions of ethical considerations make researchers aware of the following:

1. The research may have certain effects on the people with whom the research is concerned and who will be interested in the phenomenological work. They may feel discomfort, anxiety, false hope, superficiality, guilt, self-doubt, irresponsibility- but also hope, increased awareness, morale stimulation, insight, a sense of liberation, a certain thoughtfulness, and so forth;
2. There are possible effects of the research methods on the institutions in which the research is conducted. For example, health practices may be challenged or changed as a consequence of the increased awareness of the experience of birth by the mother, child, and father;
3. The research methods used may have lingering effects on the actual "subjects" involved in the study; and
4. Phenomenological projects and their methods often have a transforming effect on the researcher himself or herself. Indeed, phenomenological research is often itself a form of deep learning, leading to a transformation of consciousness, heightened perceptiveness, increased thoughtfulness and tact, and so forth.

Ethical issues take different forms at varying stages of the research. Generally, ethics is understood in terms of their lifelong obligations to the people who have become involved in the research.

This chapter discussed the methods of investigation of this study. Results of this study, data analysis, findings of the data analysis and a conclusion to the findings will be discussed in chapter four.

CHAPTER FOUR

Results of Study

The purpose of this study was to interview successful blind adults and discuss with them the following two questions, "How did you experience school?" and "What did those experiences mean to you?" Chapters one through three introduced this study, reviewed the literature necessary to prepare for this study, and discussed the details of the methods in place to conduct this study. Chapter four will review the methods of this study, discuss the data analysis and present the findings of the data analysis.

Review of Methods

Co-researchers were nominated from either the Canadian National Institute for the Blind (CNIB) or the Alberta Society for the Visually Impaired (ASVI). Nominations were based on criteria defining successful blind adults. The CNIB and ASVI received copies of the criteria. Six individuals were contacted and interviewed for this study, two from Edmonton, two from Calgary, and two from Kelowna. Interview candidates were contacted by telephone to confirm their participation and to arrange a convenient meeting time and place for the interview. The researcher interviewed all candidates in their homes. The interviews lasted approximately two hours. The interviews were taped on two different tape recorders and later transcribed. The researcher reviewed the tapes and matched them to the print copies of the interview to ensure their accuracy. The review determined that the print copies of the interview were an accurate reproduction of the interview. Following is a brief description of each of the co-researcher's backgrounds and school histories. This information has been presented in the order that the co-researchers were interviewed.

Diana lives in Calgary with her husband and two teenage daughters. She is presently self-employed as a freelance writer and computer trainer, specializing in teaching individuals who use adaptive equipment. She has also worked extensively in the field of rehabilitation and consulting for assistive technology and telecommunications. She is a public speaker, primarily addressing disability issues around advocacy and disability in the work place. Diana is on several provincial and national boards as a disability advocate. Born in Vancouver, she spent the majority of her childhood and adolescence in the rural community of Williams Lake, BC. She was two and one half months premature and, as a result, her retinas were damaged at birth because of exposure to an enriched oxygen source. Her mother was very intuitive and made sure that Diana was included in family activities. There were no kindergarten facilities in Williams Lake so when she was five years old, her mother organized her own kindergarten program. Diana was sent to The Jericho Hill School for the Deaf and Blind, in Vancouver, at the age of six. Her mother was very unhappy about having to send her away to school, but realized that a strong basis in Braille was essential for her daughter's education and this was something that neither she nor the local school could provide. At the same time, however, her mother saw this time away from home as strictly an interim measure, and immediately began a campaign with the local board advocating for her return to the community school. Success was not achieved until the end of grade three when the board finally agreed, however, they did attach several conditions to the return to her local school. These conditions were: (1) the grade four teacher had to agree to have her in the classroom; (2) Diana had some means or written communication other than braille; and (3) if she failed a grade, she would have to go back to Jericho Hill. That summer her mother taught her to type and she began grade 4 in her community school. She attended school in her community until she graduated and went on to attain a Bachelor degree in vocal performance, at University of British Columbia.

Ross lives in Cochrane, Alberta. He is married and has a daughter. Ross graduated from the University of Alberta. He earned a Bachelor of Recreation degree. Following university he worked for several years in jobs associated with government programs. Approximately 15 years ago he started working with the Alberta Park System. Presently, he manages the William Watson Lodge, in Kananaskis country. The lodge is a large facility for senior citizens and persons with disabilities in the picturesque setting of Kananaskis country. In conjunction with his job, Ross also sits on the Kananaskis Operations Team which deals with the day to day operations of Kananaskis country. In addition to his job at the lodge, Ross is also involved in politics. He is a town councilor in Cochrane and sought the Progressive Conservative nomination for the Banff-Cochrane area. Ross was born in small town Alberta. He was shot in the eye with a pellet gun and blinded when he was 10 years old. Within two years of the accident, his other eye became sympathetic and also went blind. He was then 12 years old. He lost some schooling as a result. He was sent to The Jericho Hill

School for the Deaf and Blind, in Vancouver, for grades four through nine. He returned to his hometown to complete his high school education.

Wendy lives in Edmonton with her husband and three children. She is presently studying to become a chartered psychologist. She spent many years working in the social service field. Wendy was born on a farm near Lougheed, Alberta. She was the third daughter in a family where the eldest, 8 years older, was also blind. By the time Wendy started grade one at the public school in Lougheed, her parents had fought and won many battles to make integration possible for their daughters. Wendy wore thick glasses, fashioned after the Feinblum lenses her parents had earlier obtained for her sister in New York. Dr. Feinblum had a practice in New York where he fashioned specialized glasses to improve eyesight with specific eye conditions. The janitor attached a large board to her desk and her parents provided a lamp which clamped to the board. She wrote in huge letters with white chalk on a black desk top board. Her mother taught her to read using these same giant letters in the light from a sunny kitchen window. Her family purchased a typewriter, her older sister taught her to type and in grade one she used a typewriter at school along with an enormous black pencil. Wendy's family, friends and teachers read textbooks to her. Their home was visited annually by the Field Secretary from the CNIB. When Wendy was in grade five, she learned braille by correspondence under the supervision of the CNIB Home Teacher. She found it so convenient that she completely gave up trying to read print, though she continued to type for the benefit of sighted readers. She attended grades seven through nine at Jericho Hill School for the Deaf and Blind in Vancouver. She returned home for grades 10 through 12 at Central High in Sedgewick, Alberta. Braille materials for math and French were made available through the Department of Education. All other subjects were made possible by family and friends who spent many hours reading to her.

Doris works as a rehabilitation worker for the CNIB in Edmonton. She lives independently, in a condominium very close to downtown Edmonton. She was born on a farm in the Rimby area and was the youngest of 10 children. She was born with glaucoma and spent much of her young life travelling with her parents to Edmonton and Calgary to see eye specialists. When she was seven years old, she went to the San Francisco Children's Hospital. In San Francisco the specialists did some treatment and research for several months. She was alone during this time because her parents had to return home. They had a farm and nine children that required attention. When she returned from San Francisco, her parents had to decide what they were going to do about her schooling. Doris attended her community school until the third grade. At that time, the CNIB became involved and recommended that she attend the School for the Blind in Brantford, Ontario. She attended this school until she graduated from grade 12.

Paul and Mary Ellen live in Kelowna, BC. They are married and have three small children. They are both blind. Their children are all sighted. They live independently and own a van. They have hired a driver for the van. Once a week Mary Ellen has someone assist her to clean the spots that she misses when she cleans. Paul works as a psychology professor at the university in Kelowna. Mary Ellen is presently a homemaker but has been active as a rehabilitation worker. Paul trains guide dogs and teaches orientation and mobility skills. Mary Ellen is very active in their local La Leche League. Paul and Mary Ellen are very active in the organization, National Federation of the Blind - Advocates for Equality. This advocacy group is just getting started in Canada. Paul is the founder and president.

Paul grew up in Montreal and came from a family background where education was a priority. In Quebec, the only place that children with blindness could be educated was at a School for the Blind. Paul remained at the School for the Blind throughout his school career.

Mary Ellen was born into a working class family in Toledo, Ohio. Her parents did not want to send her away to a School for the Blind, so they advocated to have her stay at the local school. With some "hassle", they were finally able to facilitate the development of a special class in one of the city schools. She had to be bused to this school. During her time at this school, she was registered in the braille class and integrated into the regular classes at various times throughout the day. She remained in the public school system for the first eight years and then changed to the Catholic School to finish her high school. According to Mary Ellen, she made this change to facilitate going to school with her friends.

The print copies of each transcript were used to analyse the data. These print copies are available from the author. The process of data analysis is described in the following section.

Data Analysis

The data from this research were analysed through a process that van Manen (1994) referred to as thematic analysis. "Thematic analysis is the process of recovering the theme or themes that are embodied and dramatized in the evolving meanings and imagery of the work" (1994,Van Manen, p. 78). This process intends the researcher and co-researchers to make something of the text by interpreting the meaning through discovery, insightful invention or disclosure. A thematic understanding could represent the structures of the experience. To understand the structures of the experience that the co-researchers had in school the following process was followed.

The interviews were printed with the interview text on the left-hand side of the paper. The right-hand side of each sheet had three columns with the following headings, codes, categories, and themes. As the interview text was read, the idea or thought from each sentence or group of sentences was paraphrased and written into column one beside the appropriate sentence(s). This process continued until the end of the interview. During the second reading of the interview, the researcher reviewed the codes in column one and confirmed a match with the sentence(s) that it was representing. Also the researcher was searching for categories that would accurately represent the codes. This information was recorded in column two. Column three was used to group categories into possible themes, as they emerged. This process was repeated for the other five interviews. The interviews were analysed in the same order that the interviews occurred.

Following the analysis of the final interview the categories were rewritten, one under the other, on separate sheets of paper. This column of categories was printed down the center of each page. The researcher then reviewed these categories for possible repetitions of categories and removed any that were repeated. The column of categories was used as the working document to group categories into themes or structures of experience.

The structures of experience or themes were then written as a draft copy of the findings. This draft was returned to the co-researchers for their validation or refinement of the information. The co-researchers read the draft copy of the findings of the study and then returned the draft copy with written feedback. All feedback supported that the information presented in the "results" chapter was an accurate representation of the structures of their school experience. These validating comments were also accompanied with more stories to provide even further enrichment to the themes presented. These additional comments have been incorporated into the final draft. Following this process, we have agreed that this chapter correctly represents the structures of their experiences in school.

During the data analysis process, it was determined that the amount of data collected was adequate for this study. According to Morse (1994), "adequacy is attained when sufficient data have been collected that saturation occurs and variation is both accounted for and understood" (p.230). The data for this study were consistent from all co-researchers. New information was not emerging and therefore the researcher felt confident that the topic was saturated and therefore the data collected were adequate. In the next section the themes that developed through this process of analysis will be discussed.

Findings of the Study

As the structures of experience began to unfold, many questions came to my mind about how belief systems were developed within individuals and how expectations were established. Therefore, during the data analysis process, I saw the need to review theories of learning. Hergenhahn (1988) reviews theories of learning and attempts to place learning theory in a historical perspective. He also presents some of the essential features of the major theories of learning and examines their relationships with educational practices. Of particular interest to me, was Hergenhahn's (1988) presentation of Edward Tolman's theory of cognitive mapping or learning as the acquisition of a cognitive structure. Hergenhahn (1988) reported that Tolman took his lead from the Gestalt theorists when he stated that learning is essentially a process of discovering what leads to what in the environment. For example, according to Tolman's theory, rats learning to solve a maze learn the spatial layout of the maze, and not a series of movements in response to specific stimuli. The organism explores and discovers that certain events lead to certain other events. According to Tolman, what is learned is the lay of the land. Gradually a picture of what is available in the environment begins to form. Tolman referred to this picture as a cognitive map.

Individuals with blindness, learn to travel independently because of cognitive maps that have been developed. These cognitive maps are developed through the process of utilizing sensory information to form ideas of space and the environment. These cognitive abilities develop as they interact with their environment. Cognitive maps begin to form as these individuals receive information about distance, direction, and environmental changes.

During the development of the cognitive map, expectations are utilized by the individual. Expectations are hunches concerning what leads to what. Early tentative expectations are called hypotheses and they are either confirmed by experience or not. Hypotheses that are confirmed are retained and those that are not are abandoned. An expectancy that is consistently confirmed is commonly referred to as a belief. When an expectation is consistently confirmed, the individual ends up believing that actions result in certain reactions.

It was important for Tolman to distinguish learning and performance. We can think of performance as the translation of learning into behavior (Hergenhahn, 1988). According to Hergenhahn (1988), Tolman's theory states that we know many things about our environment but act upon this information only when we need to do so. Therefore, individuals bring to a problem-solving situation various hypotheses that they may utilize in attempting to solve the problem. These hypotheses are based largely on prior experience. For the purposes of this study, problem-solving situations associated with blindness will be discussed as challenges.

As I read about Tolman's theory of cognitive mapping, I thought about how the development of the belief system applied to this study. I considered life as a stage, stretched out before individuals. Ahead of them, are their expectations of life. As they travel and those expectations are confirmed, they build their belief systems. Thinking about this stage, and actually visualizing it, the themes from my research float into my mind, take form and find meaning with respect to the stage of life.

In a literal sense, passage across a stage that is flat may feel comfortable and in most cases manageable. Therefore, we continue to move across it day by day, learning, growing and playing out our lives.

Along the way, we may meet challenges or problems that can offset the balance of this stage. The nature and intensity of the challenge will vary from situation to situation and individual to individual. The more severe the influence of the challenge, the greater the tilt of the stage. A negatively influenced challenge would offset the stage in an upward direction, making the journey difficult or impossible. An upward tilt of the stage may make the journey feel temporarily interrupted until the problem is resolved so that the stage rebalances itself allowing individuals to feel that they can continue. A journey that is interrupted or made difficult may need positive influences to rebalance the stage. For example, a positive influence would offset the stage in a downward direction, creating the feeling that movement across the stage is quicker, more invigorating and exciting.

The individuals interviewed for this study were nominated as successful adults with blindness. Blindness may impose many challenges for an individual and therefore create many opportunities for their stage to become tilted. For some, this tilt is severe and their journey is greatly impeded. Individuals that fall into this category may be unemployed or possibly living lonesome and unfulfilled lives. Successful adulthood may mean that the challenges faced earlier in life have been minimized and balanced. The data from this study revealed the challenges of blindness that structured the school experience of the co-researchers. The most important information from this study revealed those forces that may have influenced co-researchers positively. These positive influences perhaps maintained the balance of the stage.

The data from this study revealed that the structures of experience consisted of polarizing factors that were represented by challenges of blindness and positive influencing factors. These polarizing factors were categorized within three major themes. Each of the factors was associated with feelings. When the feelings were examined separately, it appeared that they were also polarized. Initially, it was thought that negative versus positive feelings would be a theme. However, feelings were abundant throughout all the data and therefore the polarizing factors of feelings will be discussed separately as a global theme associated with the other three. The discussion of negative and positive feelings follows the discussion of the three themes.

These opposing forces have been presented within the discussion of the following themes: (a) being disconnected versus the need for belonging; (b) being unprepared versus being prepared; and (c) inhibiting behaviors and facilitating behaviors. As the co-researchers disclosed their school experiences, evidence evolved which supported each of the opposing sides of these themes. Within each theme, examples appeared that indicated negative influences which possibly influenced the balance of their stage or the stage of their parents and teachers. Co-researchers revealed factors that may have influenced the rebalancing of these stages. It is important to note that the co-researchers provided many examples of very challenging situations. During the interview and in the time following the interview, I was not aware of the abundance of these examples. It was not until I analysed the data and began listing examples of the challenges, within theme areas, that the possible impacts of these challenges were realized. The co-researchers had left me with the feeling of excitement and enthusiasm. Initially, I imagined the structures of their experience as pillars, holding up their stage. I had not realized, at this point, that I would find polarizing factors that affected balance and rebalance of the stage. The co-researchers presented very significant challenges from such a positive and successful perspective that I cannot help but consider how powerful the positive factors must have been in their lives.

The discussion of each theme will begin with an examination of those negative challenges followed by the positive or balancing factors. The data collected did not support any theme more strongly than any other. It appeared that the factors presented within each theme were equally experienced among co-researchers. For this reason the themes are not presented in order of importance. Theme one is being disconnected versus the need for belonging and will be discussed in the following section.

Theme One - Being Disconnected versus The Need for Belonging

I found the theme of being disconnected versus the need for belonging particularly interesting because of my interest in Mitchell's (1992) work in the area of identity. The element of connectedness is a part of the nuclear ingredients for the process of forming an identity. Co-researchers presented as successful adults with blindness and expressed a strong purpose and place in life.

The findings of this study, as it relates to the theme of being disconnected and the need for belonging, will be discussed in two sections. Section one will demonstrate how the elements of disconnectedness were found in statements about pain, residential schools, parenting roles, praise for ordinary behaviors, low expectations, culture and language. Testimony from the co-researchers indicated that blindness can create situations for individuals that may make them feel disconnected from family, social groups, peer groups, or their own bodies.

Being Disconnected. Being disconnected is associated with feelings of lonesomeness, fear and helplessness. It is a difficult feeling to make sense of because your physical presence gives you one message and your brain and heart tell you something different. For example, I cuddled and comforted my son (physical presence) but my brain and heart told me that I was not reaching him.

In this situation, our son's pain is clearly representative of disconnectedness for him and myself. His pain was so great that he was unable to participate as a member of our family. He was unable to eat, sleep or pay attention to activities going on around him. He assumed the fetal position and there he stayed for what seemed like an eternity to our family. My son was disconnected from our family and from himself. Doris was sent away from her family so that she could see specialists in San Francisco. She experienced pain associated with her eye disease. She was disconnected from herself during periods of extreme pain. She was also disconnected from her family because, at 7 years old, she was away from home for approximately 3 months.

Many of the co-researchers were sent away from home to attend school at residential schools. The distance between their homes and the school was great and they did not get the opportunity to visit with family. Doris only returned home for summer vacation. She reported, "Newsletters came out and we were encouraged to write home . . . my parents came down to Brantford twice . . . once my brother had an exchange or something in Ontario and he came to visit me once. But other than that nobody came down." She went on further to explain, "It did draw me away or pull me away a bit from the family because you miss family events." Ross equated his experience in Jericho Hill to being in prison. He thought it quite ridiculous that the school staff would seek his parent's permission to allow him to leave the campus to go to the corner store. His parents were a province away.

When professionals get involved with children, who have significant vision loss they may present as knowledgeable and comfortable with blindness. If they use this knowledge and comfort to take control, they may intimidate parents. According to Paul, some parents have given up their responsibilities and duties as parents in what they believe to be the best interests of their child. He feels that professionals have created the feeling that you have to be trained to be involved. He reported, "Many of the parents were willing to leave the responsibility of bringing up the blind children to the nuns, because they felt that the nuns knew best." Therefore, parents step aside and allow the professionals to direct. Paul believes that, "Professionals have professionalized blindness and therefore taken the responsibilities away from the blind culture." Mary Ellen stated that she thought her mother believed that she couldn't teach her to cook because she was not a specialist.

Parents, teachers, and significant others can give the message of disconnectedness in a number of different ways. One of these ways is offering praise for ordinary behaviors. If individuals with significant vision loss are praised for ordinary things, they may acquire the message that they are not capable of doing any better. These messages could be very confusing to individuals with significant vision loss and they may be at risk for feeling disconnected. Mary Ellen's reported that her parents advised her, "When people say you're wonderful because you do ordinary things, they're just saying they don't expect much of a blind person and because you are doing more than they expected, then you are amazing. But they have low expectations and you can't take those compliments very seriously." She felt that her biology teacher gave her an A for breathing and Ross felt that his gym teacher gave him passing grades for showing up. Mary Ellen testified that there is a tremendous amount of satisfaction for getting a compliment when you have really worked at something and therefore you deserve the compliment. Ross talked a lot about getting praised for doing the ordinary. He supported Mary Ellen's claim that such compliments only makes you feel more different and less like you belong.

Mary Ellen tried for a good portion of her youth to belong in the sighted world. She witnessed the public scorn toward blindness and spent much of her youth wishing that she was sighted. She reported, "The principal made it pretty clear that we weren't really fit to be with normal children and I was so embarrassed because I hadn't been misbehaving and that just really alienated me from the other classroom people, because I really wanted the principal to like me and so I was just really embarrassed and trying really hard to separate myself from other blind kids." Her blind friends embarrassed her. She was neither connected to the blind community nor the sighted community. She was terrified of doing something that might make her look blind. She thought she had to be perfect to be accepted. The benefit for her was that she set high standards for herself. She felt like a second class citizen. She was very conscious of the fact that her perceptions told her that there were two different sets of standards - standards for the blind and standards for the sighted.

In Paul's situation, he was not only disconnected from his family but he was disconnected from his culture as well. The school was French speaking and he longed for the English language. He revealed, "There were kids that would come over, sometimes on weekends, and play but a lot of things that I knew about they couldn't relate to because they were French. They didn't watch the same TV shows that I did. They didn't read the same books that I did. So there was a lot that they didn't relate to and so there was always something missing with these kids. They were from a different culture and that was a very big factor." Also, during one of his school years, he was the only boy in the class.

The next section will discuss factors addressing the need for belonging that were found in statements about love, caring, integration, advocacy groups, competition, responsibilities, and expectations.

The Need for Belonging. To belong is to feel fulfilled. Experiences of belonging are associated with love, caring, connecting and commonalities. To belong means that you are a part of a whole. Many of the co-researchers talked about the love and care they felt within their families. Wendy reported, "We weren't any different from any other farm people . . . we did things in more of a family context . . . we belonged." According to Mary Ellen, "It was a strong family with an extended family." At another point in the interview, she added, "My parents were determined they would do what they could and try to help me lead a normal life." Fond memories of farm life or summers at the lake made their way into the interviews. Paul testified, "I cultivated a lot of friends at the lake, I became very attached to the United States (location of a lake cottage) at that point, and still am, it stayed with me." Doris revealed that one of the major things she was missing at Brantford was, "the closeness of a family." Diana and Mary Ellen shared stories about determination and drive demonstrated by their mothers when they were seeking an educational placement. Mary Ellen recalled a friend of her parents telling them, "There is no substitution for a mother's love." According to Mary Ellen, this comment assisted them in the decision-making process because, "They spent a lot of time trying to decide what to do about my education because at that time really the only option was the School for the Blind in Columbus, Ohio, which was a two and one-half hour drive. My parents got determined and got together with other parents and formed a parent support group, for the preschool blind and started lobbying the school system."

Good situations for the co-researchers were closely associated with the comfort level of the persons with whom they were interacting. Teachers who left the impression that they were comfortable with the blindness and appeared to be interested in the individual were the teachers most fondly spoken about. Ross stated, "I just think you need decent and realistic mentors as teachers." He had a gym teacher that he described as a person with "standards that were just so much higher, he expected me to do it."

Doris spoke directly to the issue of integration when she said, "integration doesn't just happen, you have to be the kind of person or do the kinds of things that's going to draw people to you or you have to go to them." Integration should mean belonging. At the School for the Blind in Brandford, Doris reported, "I was meeting other blind people and I was not different. I was the same as everybody else and learned braille right away which was really good because then I was doing things everybody else was. At a regular school I was doing the same thing as everybody else but I couldn't read. So in essence I wasn't doing the same as everybody else. Here I could participate, I could really do the work." She expanded further to say that integration could work if we, "Find an interest, don't just expect interests to come to you, but have a passion, have interest in things that are fun and get involved with groups that are in those sort of things." She believed that it was difficult for a blind person to become involved in a big social atmosphere. Small interest groups worked better for her when she wanted to get involved. Wendy's advice to parents is to expose your children to a lot of different experiences. If children have a lot of opportunities to try a lot of different things, their parents will have a better opportunity to find out what they are interested in doing. Parents should then support them and cultivate the passion. Wendy also felt that it was important to teach children with blindness to be a good friend. She reported, "I think that the parents, in their grief at having a child with a disability, are often quite busy integrating their own child and they forget that the child, with significant vision loss, needs to have things to give to other people, whatever these things are, and ways to exercise giving . . . sharing those things that I had with other people, that's important." Issues such as sharing and being considerate are important human values that must not be overlooked because of blindness.

Paul and Mary Ellen speak from experience when they advise becoming part of the National Federation of the Blind - Advocates for Equality. Advocacy groups, such as theirs, bring people together who have common issues and interests. According to Mary Ellen, "They can provide a lot of support through networking and collection and circulation of information." The National Federation of the Blind - Advocates for Equality taught Mary Ellen something about blindness, in essence because of this advocacy group she learned how to be blind. If Paul were addressing an audience of children with blindness, he would advise them that, "It is of the utmost importance that you bring your parents to the Federation because it is through the Federation that they will meet blind people who are living lives that they aspire to live."

The data suggested that it was important for parents and teachers to assign responsibilities to individuals with visual impairments. Chores at home, commensurate with the other siblings, were an important part of a normal upbringing. According to Doris, "My brothers and sisters were not overprotective, they insisted that I learn to do things, and I wanted to, I wanted to learn how to milk a cow, I wanted to learn how to do chores that I had to do and that kind of thing."

Teachers should not overlook students with visual impairments for positions such as team managers, council membership, or other leadership roles. Essential for the co-researchers were the feelings of being a part of a team and most importantly that they were a contributing member of that team. Wendy revealed that she "feels quite grateful for all the opportunities that I was granted to be like everyone else."

The co-researchers agreed that an important aspect for them, when they were growing up, was the visualization of life after school. This concept is important to the theme of belonging because their sighted peers were expected to go onto post-secondary education, marriage or employment. Ross talked about going to university because it was something he really wanted to do. He said, "I actually don't know if I was expected to go to University. I always told all of my teachers that and they'd always smile and say, 'that's great, Ross'." His teachers' actions did not always support these verbal affirmations and therefore he did not trust that his teachers really agreed. Ross continued to believe and dream that he would go to university because of his successes at Jericho Hill. Mary Ellen and Paul's parents believed they would go onto post secondary training because education was valued in the households. However, they did not believe that they would marry, have children, cook, and so forth. Pauls' parents did not want him to marry someone who did not have sight. They thought that he needed sight in the household. He told his parents that you could have sight in the household but you didn't have to marry it to get it. When Paul was asked if his parents still felt this way, he replied, "I don't think so, no. My mother said before she died that she hoped that we'd have a second child and now we have three. I think that they would be very proud."

Ross spoke very highly of competition. He recommended the importance of participating in competitive situations. Competition created an area where all are judged according to the same set of rules. This area fostered connectedness. Ross connected with fellow athletes because he competed in sports and was very successful.

Theme one examined those experiences that created challenges for the co-researchers and their significant others relevant to the theme of being disconnected versus the need to belong. The co-researchers disclosed many examples of disconnecting experiences and behaviors from a very positive perspective. According to Doris, "We were just talking about life. Everyone has negative experiences." Doris' comment demonstrated her connection with everyone else. She has demonstrated her sense of belonging. It is possible that with the significance of the negative challenges, the positive factors must have been very powerful.

The following section will discuss polarizing factors representing theme two. These polarizing factors are discussed in two sections, being unprepared versus being prepared.

Theme Two - Being Unprepared versus Being Prepared

The theme being unprepared versus being prepared was equally expressed by all researchers. The co-researchers discussed elements of this theme in reference to preparedness or lack of preparedness from the perspective of themselves as well as their significant others. Factors related to both of these perspectives are presented in the discussion of this theme.

According to Webster's New World Dictionary (1990), preparedness refers to "the state of being prepared or making oneself ready" (p.464). Blindness may threaten or challenge an individual's journey across the stage of life. The degree of the threat will probably be influenced by those factors in place to support or prepare for the threat. The presentation of the theme, being unprepared versus being prepared, will discuss those elements of being unprepared that threatened the journeys' of the co-researchers. The co-researchers experienced elements of being prepared which greatly influenced them and facilitated recovery from the threats of being unprepared. Being unprepared versus being prepared will be discussed in two sections. The first section will present the findings of this study as it relates to being unprepared. Being unprepared could be seen in statements about lack of opportunities, leadership, lack of information, bad habits, low expectations and politics.

Being Unprepared. The state of being unprepared can be experienced in many ways. Feelings associated with unpreparedness include fear, inadequacies, lack of confidence, and lack of control. Being unprepared can mean individuals feels that they do not have the ability to control their environment. The data from this study revealed that the co-researchers experienced the lack of everyday opportunities and effective leadership. They reported that significant others did not have an understanding about blindness and access to information about blindness. The co-researchers talked about bad habits, which were cultivated throughout school years. These bad habits presented as obstacles for them as they approached the end of their school careers. Consistently, the co-researchers agreed that they experienced situations in which they were not aware of any expectations about their performance, appearance, and their role in life after school. It was reported that politics created situations which were challenging. These factors support the theme of unpreparedness and will be discussed in more detail in the following section.

Doris talked about the importance of growing up in a large family. Her brothers and sisters carried the attitude that if they had to do chores, so did she. She expressed that she wanted to keep up and happily did her share. Doris reported a change when her brothers and sisters started to move away from home. She reported, "I didn't like overprotection, but I did know what overprotection was because my mother was a bit overprotective. My brothers and sisters were not, they insisted that I do things." She no longer experienced the benefits of their leadership in expecting her to participate.

The co-researchers agreed that blindness created a situation where those individuals who have never experienced blindness usually did not demonstrate the ability to understand what the experience was like. The implications of this lack of understanding could be a lack or lowering of expectations for the individuals. Diana reported, "People did not know what to do when they saw me." She elaborated with,

". . . the whole fear thing around something you don't know, they close their eyes and they think that's what it would be like for them." Doris grew up with her brothers and sisters. They were comfortable with blindness and expected her to be just like them. The general public, on the other hand, probably did not have this comfort level and therefore they were unprepared for situations they encountered.

Four of the co-researchers came from small towns. Blindness is a low incidence disability and limited access to people, because of a small town setting, created isolation factors. Ross reported that there were not individuals in his hometown with whom his parents could consult about the implications of vision loss. The teachers in his school were unprepared to teach a student with blindness. Ross reported, "We base the decisions we make on the experiences that we've had . . . if you are making decisions on behalf of a child that you had with blindness, in terms of appropriate school settings, how would you make those decisions?" They did not have the resources, the materials or the guidance and support to create the know of 'how to do it' for them. They were left, basically, on there own and therefore were not in a position to make educational choices on Ross's behalf. When Ross returned to his home school in Calmar, he revealed, "I became a special education student for the first time. My marks just plummeted . . . My study habits went downhill, my attitude toward education went downhill and I had absolutely no respect for my teachers, where I think I used to." Wendy reported that the lack of access for school materials created an attitude of, "they don't need them anyway." Diana reported that she had to do more and more work at home. Her mother would read the material to her and together they would work on the assignments. If modifications applied to the work assignment, Diana's mother would modify them so that she had access. Both teachers and parents in this situation did not have access to resources or persons with whom they could network. They were unprepared for Diana.

Diana encountered situations in school which clearly demonstrated that her peers did not understand blindness and were therefore unprepared. For example, Diana reported, "I used a peg board for working out math questions. The placement of these pegs on the board allowed me to tactually manipulate the numbers in order to do computations. The kids didn't understand that the pegs were my answers. Occasionally, they would come along and change them."

Ross talked about the lack of opportunities to participate when he returned to Calmar. At the School for the Blind, he was very active physically. He swam and was on the wrestling team. In Calmar, the gym program was totally unequipped to support him. The students were involved in team games such as volleyball and basketball. There were no wrestling teams and no swimming pool. The gym teacher made arrangements for Ross to participate in a weight program. So for three years he worked with weights in gym. Ross revealed, ". . . for 3 years I went to the weight room during the gym. And some days there was a back door to the weight room and I'd walk in the front door and out the back door, you know. And all I needed to do was show up at the gym class. And I was marked as a pass, because it wasn't really expected that I would do those things." Paul provided further evidence when he reported the limited opportunities that he had at his school to participate in athletic activities.

Several co-researchers expressed concerns about levels of support in the school system for students with visual disabilities. Doris' experiences as a rehabilitation therapist left her with the impression that too much is done for students with visual impairments. Teacher assistants are hired without proper training regarding their duties of providing support to students with visual impairments. When Doris was working with one of her students, she found herself quite alarmed that this girl had graduated yet did not know braille. She asked the girl how she was able to graduate and the girl testified, ". . . I had a teacher's aide and she would do all of this stuff for me." Doris suspected that the teachers' assistants are making work easier for children rather than challenging them to advocate for themselves and figure things out on their own. Diana reported that too much assistance fosters unrealistic expectations and as a result students are unprepared for life after school when those supports are not there.

Paul and Mary Ellen revealed that parents and teachers who are not prepared for dealing with visual impairments may marginalize the situation. Individuals who marginalize a situation may believe that those participating will never excel, at best they will meet adequate expectations. For example, Mary Ellen reported that, "A student from the braille program ran for school office and won the election. The principal was viewed as one who marginalized the students from the braille program. This principal probably let the girl run because of the belief that she could never win anyway. When the girl won, the principal would not let her hold the office. The parents and her peers had to become involved to create enough pressure for the principal to change her stand. The principal at this school was openly opposed to housing a program for blind students." The school board gave her the choice of having the braille class or providing a program for another disability. According to Mary Ellen, the principal probably decided that the program for the blind was less trouble than others may be, so she decided to have the program stay.

Under this leadership, the teachers in this school did not take responsibility for teaching these students in their classrooms. According to Mary Ellen, ". . . it was not the teachers' job to see that we managed or did well enough, if we didn't fit in, then the teacher of the blind had to figure out a way to fix it."

The co-researchers shared opinions that many children with significant vision loss are unprepared for transitions from one life experience to another. Ross testified that he was totally unprepared for the University of Alberta. He not only faced the challenges that his sighted peers were facing but also had to resolve issues such as locating and navigating to strange buildings. He did not know how to locate materials for himself. The university bookstore did not carry braille or audio copies of recommended course materials. Going to the bookstore to obtain materials necessary to prepare for his courses was not an option.

Individuals with significant vision loss are reliant on others to share important information with them about social conventions. They must learn to trust others and believe that they have been given the correct information. If individuals with significant vision loss are not prepared to receive this responsibility there is the possibility that important information will be withheld from them. For example, traditionally we do not tell individuals when they have dirty clothes or a body odour. In most cases, we are not comfortable to provide this information. Without this information, individuals with vision loss may endure consequences such as isolation or embarrassment. Sadly, they may not understand the reason for the consequence.

The elements of unpreparedness that have been presented provide some insights into the challenges that being unprepared can create for individuals with significant vision loss and for individuals closely associated with significant vision loss. The next section discusses those aspects of being prepared that may provide assistance in balancing the stage to facilitate the journey across the stage. Elements of being prepared were found in statements about early intervention and referral, concept development, opportunities and resources, structure and routine, equal access to information, and skills to manage blindness. These elements will be discussed in the following section.

Being Prepared. Several participants expressed the opinion that early referral to knowledgeable persons provided teachers and parents with the confidence to implement what their common sense was telling them to do. With this support, individuals may feel that they are prepared to deal with the situation and therefore they should be involved. Appropriate support from knowledgable individuals may facilitate healthy relationships between professionals and parents. Parents may feel that their relationships with the professionals are collaborative rather than dependent.

Diana's reported that her mother demonstrated the importance of early intervention through her attempts at preschool programming. Diana felt that her mother recognized that she was going to access information through the use of her hands and ears and began to plan a program which addressed development of skills in these areas. Likewise, Mary Ellen's revealed that her parents advocated for a preschool program for her because she said, they felt she needed the social experience of being with other children.

Closely related to early intervention programming was concept development. Diana stated, ". . . I found that process was missing in a lot of the adults who came back to learn daily living skills, or what we called 'adjustment to blindness' training. They heard all the same sounds I heard, but nobody had provided them with any reference points or talked about how to relate those sounds to what was actually going on in their environment." Diana reported that her mom included her in everything. She took her shopping, prepared her for school and taught her about body images. Diana learned in functional ways. Diana shared this story about her mother; "One day Mom and I were having a conversation about people's inability to see around corners. I couldn't understand why my mother was not able to look at what I was doing in another room. I thought that because I could hear her, she should be able to see me." Wendy emphasized the importance of not making assumptions.

Ross talked about the significance of the opportunities afforded to him at the Jericho Hill school. He fondly recalled the days of membership on the wrestling team, swimming in the pool and access to quality instruction. He testified that the quality of staff was high because of the proximity to the university. He said, ". . . we were certainly given the opportunity to achieve and encouraged a lot both physically and academically." Ross reported that the teachers had a curriculum that they followed and everyone was expected to achieve that curriculum. There was no distinction made between students' abilities. There were no special education students. He reported, "It was a normal school situation."

Doris reported that the school for the blind created more social opportunities for her and provided access to different kinds of activities. This provided her the opportunity to experiment with a number of different activities as she developed interests. Doris reported, "I was able to participate in choir and music lessons, all kinds of just excellent, excellent music experiences at school."

Wendy addressed the area of literacy and the importance of developing skills to manage blindness. She stated, ". . . management skills, the kind of skills that allow you to have your act together and tell people what the best way is to help you and what things you can do, because the better you can do that for other people then you can just get on with whatever has to be done and the more quickly it will be done." According to Mary Ellen, ". . . nobody else is responsible for your life but you as you grow older and the more skills you have, the more flexibility you'll have."

All co-researchers agreed that access to information was essential. Doris and Wendy talked about the accommodations that were made for them at school when the teacher had the other children reading to them. Small classes appeared to be a positive influencing factor. Ross explained that if he were shopping for a school for his child, he would chose a classroom that had smaller numbers because smaller numbers facilitated more contact with the teacher and provided a more workable social grouping. In a smaller class, perhaps, the student has the opportunity to feel more in control.

Many co-researchers revealed an understanding of their own needs and talked about how they learned to self-advocate. Wendy stressed that it was very important to learn how to use help. She said, ". . . don't think you can manage without help, because you can't . . . the best way to get help is to learn to use help, learn to make friends and make it worth their while to help you."

Co-researchers discussed how equal access to information and the development of skills to manage blindness were helpful to them. My family experienced the challenges of blindness and we were grateful for early access to information and support. We were encouraged to exposure our son to a variety of activities, structure and routine, and to pay attention to the development of concepts. Preparing for blindness has assisted us in maintaining control. The next section discusses theme three, Inhibiting and Promoting Behaviors.

Theme Three - Inhibiting Behaviors and Facilitating Behaviors

The data revealed that the co-researchers encountered behaviors of other individuals that were negatively challenging at the time. Together these behaviors create one pole of this theme, inhibiting behaviors. Inhibiting behaviors are behaviors displayed by individuals toward individuals with visual impairments. These behaviors may impede emotional or physical growth and development and included behaviors such as overprotection, rescuing, discrimination, negative attitudes, and dependencies. Inhibiting behaviors can also be behaviors, that may create a false impression, displayed by the individual with visual impairments that may create a false impression. Behaviors associated with visual impairments include head rocking, head droop, body rocking, and hand flapping. They are commonly called "blindisms" or mannerisms. These behaviors may leave the impression that individuals engaged in the behavior are less capable than they really are. Engaging in these behaviors may also prevent access to social groups or goal achievement. Inappropriate social skills may also have the same outcomes. Inhibiting behaviors will be discussed in the following section.

Inhibiting Behaviors. I engaged in inhibiting behaviors when I restricted my son from experiencing life. My own fears and lack of understanding about blindness made me feel that I could not accept the responsibility of letting him go. I did not have any confidence. I was so frightened that I would misjudge a situation and I imagined all the horrible things that could go wrong. It was easier for me to severely limit or restrict his participation. Parents and teachers may create situations for children with visual impairments where they are preventing them from being included in home, school, and community life. These situations include over-protection, rescuing and rewarding for ordinary behaviors. Doris reported that, when she came home for the summer holidays, "Socializing, going to the dances and stuff in the country, my mother discouraged it because I think she felt I was going to be hurt." At this particular time, Doris was recalling summers after her brothers and sisters moved away from home. When they were there, she always went along with them and felt quite lonely and more isolated after they had gone. In my own family my son always wants his dad to take him places such as climbing, swimming, and so forth. He tells me, "You're afraid of everything, Mom, let Dad take me."

In the previous section, appropriate support for children with visual impairments was discussed. It was suggested that too much support can leave them unprepared for life after school because they have developed dependencies or they have an unrealistic view of the realities of adulthood. According to the co-researchers, individuals providing support to children with visual impairments may also create difficulties for them if they assume responsibilities for students. Janell Wells (1996), a student with disabilities, supported the co-researchers opinions with her response on the Internet to the question, "What should classroom aides know?" Her comments include, "They are our aides, they should not be in charge of everything we do and say," and, "Aides can help kids see what they can do with a little help. They should not be there to do everything for them. We are the ones in school, not the aide!" The co-researchers also expressed that teacher assistants, teachers, and parents were not helpful when they reduced work loads, punished unfairly or differently from the other students and accepted inferior or no work. Situations where these behaviors were demonstrated may have been interpreted as rescuing students with visual impairments from responsibilities and consequences. According to Wendy, the implications of rescuing may be the communication of the message that she was not capable and therefore does she did not have to do it.

Public attitudes hurt. They can take many forms. Three were apparent in my study. The first public opinion that can be hurtful included those behaviors that demonstrated a belief that visual impairments caused an individual to perform at a more inferior level, becoming less capable than a sighted person. For example, Wendy reported, "Ross and I left Jericho Hill to return to Alberta the same year. At Jericho Hill the teachers kept up a running mythology about how hard it was for blind students to attend public schools. Most of the kids accepted their descriptions at face value, having never attended public school. Ross and I had both attended public schools and we told everybody it was quite possible for a blind student to manage. One day a man, from the Alberta Department of Education, came to visit us at Jericho. He interviewed me privately and told me I would be completing high school in four years because I was blind. I told him I would take only three years. He told me that the Alberta government was watching to see if we were successful before deciding whether to integrate blind students into public schools. He said my failure would ruin the chances for other blind students. For this reason, I had to be very careful about the decisions I made." Wendy went on further to disclose the implications that this attitude of inferiority had for her with the following statements, "At that point I found it almost impossible to remember that I had spent six successful years in public school. I dreamed that I failed a subject and the government made all my friends stay at Jericho Hill forever. Many years later, when I was a professional, working in the field of blindness, I saw this man at work-related events. One day I told him how much I resented the fact that he had made me feel so responsible, particularly when he knew that my success or failure was mine and mine alone. He just laughed and said he had only been trying to make me work hard. It is the closest I have ever come to spitting upon another human being."

Secondly, some people believe that all disabilities fall into the same category and therefore all individuals with disabilities have the same needs. Diana discussed, "When I first went to Jericho Hill, the dormitory was shared by the blind children and the deaf children. The blind children were often partnered with deaf children. I recall how confusing and scary this situation was for me and others because we couldn't understand why the deaf children made 'funny noises' and never spoke to us. This whole experience might have been positive if any of the staff had taken the time to talk about the implications of this situation and the differences between the two groups." Ross recalled unfair treatment in school through his examples of inadequate or different punishments from his sighted peers. His teachers lack of expectations clearly reinforced inferiority for him. He commented, "If I had achieved what they expected me to, I would have amounted to nothing."

Finally, some people believe that visual impairments are a burden or problem. Wendy recalled her experience at Jericho Hill in home economics class, "We were supposed to be learning how to cook. Blind children were always partnered with a partially sighted child and as a result I never got to pour anything or stir something that was hot. There were two different sets of dishes, glass ones for the deaf children and melmac for the blind children."

I have experienced the quick judgements and comments of the general public about situations where they were not fully informed of the circumstances. Many of the co-researchers reported situations in their families and school environments where public pressures prevented them from treating their children or students like normal children. Jan Bailey (1991) reported that her father took her out into the backyard and rolled her around on the grass in response to her fear of the grass. As she was screaming, the neighbours came running and told her father that he was cruel. A few days later, Jan was outside playing on the grass. Bailey (1991) stated that her father chose a strategy that he believed would work for his daughter and as a result suffered public ridicule.

Individuals with blindness adopt inhibiting behaviors when they believe that they have to be perfect in order to belong. If they believe that they do not have control, and as a result develop inappropriate dependencies on other people, they may present as incapable individuals. Mary Ellen reported that she believed that if she could read as well as the sighted kids that she would be viewed as a sighted kid.

Diana expressed the need for support regarding the teaching and development of appropriate social skills. Mannerisms such as head droop, rocking, or hand flapping may be aversive to the general public or create the impression that there may be a cognitive delay. She had the opportunity, when she was taking class from a deaf-blind individual in a rehabilitation teacher training program, to really understand why people sometimes acted uncomfortable around her. She recalled, "I remember thinking how easily it would have been to avoid this person. I felt inadequate working with him and could very easily have assumed that he was not capable, particularly if he gave me some reason to believe that this might be so. These thoughts made me realize that other people may feel this way about my blindness. I recognized the importance of a good physical presentation and appropriate social graces."

Inhibiting behaviors may create challenges for individuals over which they feel they have little or no control. The following section will discuss facilitating behaviors that were helpful to the co-researchers.

Facilitating Behaviors. My son believed that the Prime Minister needed to know who he was, so he wrote him a letter. We thought that this was quite cute and never took the mailing of the letter very seriously. We became considerably more serious when we received a call from the Prime Minister's office acknowledging his letter and responding to the request for a meeting. Our family were about to meet the Prime Minister. According to the co-researchers there are several behaviors that individuals and their significant others could engage in that facilitated the rebalance of the stage offset by inhibiting behaviors. The self advocacy demonstrated by my son in the story above is an example of a facilitating behavior. Facilitating behaviors create a forum that allows individuals to be the best that they can be.

Other facilitating behaviors discussed by the co-researchers include humour, fitness, passion or interests, understanding needs, expectations and standards, role models, positive presentation, challenges and competition, literacy, skills to manage blindness, commitment, working for what you earn, and taking ownership. Examples of situations where co-researchers experienced facilitating behaviors are discussed in this section.

Doris revealed that the most rewarding aspects of school were the experiences such as the musical performances and the fun. She recalled many humorous situations which were representative of kids being kids. She described several situations where she and her friends were having a lot of fun being very mischievous. The fun abruptly ended when they got caught. For example, ". . . somebody decided to take the screen off the window and we started throwing bedding out, pillows and things. We yelled at them to try and hit the window, and so things were getting thrown back up. And so things were flying all over the place and we finally got caught by one of our teachers."

Diana shared many humorous stories and her delight in the presentation of these stories revealed her sense of humour and positive outlook on life. Fun and a good sense of humour are behaviors that can minimize distressful situations.

Ross was very active physically through his participation in school-related sports. He appreciated the expectations and standards at Jericho Hill. Ross reported, "At Jericho, the standards there basically for achievement were really quite high . . . we were given the opportunity to achieve and encouraged to a lot, both physically and academically." He was disappointed that he did not have this opportunity in his high school years. Physical involvement for him provided those opportunities to participate on equal ground with a team mate or opponent. High expectations and challenges provided the opportunity for him to feel accepted. Meeting these challenges was rewarding to him. Meeting challenges continues to be an integral part of Ross's life.

He was a member of the Mount McKinley climbing expedition that came within 2000 feet of summitting. He continues to be very active in Kananaskis country.

Ross developed an attitude about himself that two of his teachers reinforced. He reported, "They seemed to have a knack of dropping those little time bombs on you, the statement stuck in your mind and meant absolutely nothing the day they told you, but 15 years later the light bulb goes on, and the words are in your head." These teachers made Ross feel that they were committed to him. Wendy experienced commitment from her mom. She reported, "Keeping me in local schools required more effort on the part of my parents than sending me away. People say that aides do too much for blind children nowadays. I don't dispute this, but the fact remains that somebody has to fill in the gaps if a child is to be mainstreamed. In my case, the gaps were filled so graciously by my mother that I hardly recognized the fact that hours of special help were being devoted to me. In elementary school, I wasted many hours in the classroom, doing nothing while my classmates did assignments. Then my mother and I did hours and hours of homework. In the days when there were no teaching assistants, the success of mainstreamed blind students probably depended almost entirely on the commitment of their parents."

Doris and Wendy agreed that cultivating a passion toward an interest is a behavior that would promote balance and satisfaction in the lives of individuals with visual impairments. The co-researchers stressed the importance of being exposed to many different kinds of experiences. This wealth of information and opportunities would better equip individuals to make decisions about what they are interested in pursuing.

Doris performed with the choir at her school and became very involved with the music program. Mary Ellen won a regional Junior Achievement title. The abilities of individuals with significant visual impairments to perform and to achieve assists the general public to understand their potential. The successes of all the co-researchers may help parents, children with vision loss and the general public to adopt positive attitudes toward visual impairment.

Role models within society are generally individuals who are admired, looked up to, and respected. Their behaviors are observed and those who like what they see, copy or model the behaviors. Successful adults with blindness facilitate the development of high expectations for individuals with visual impairments. They provide hope and comfort for parents of children with visual impairments and individuals with visual impairments because they provide some sense of future for them.

The co-researchers agreed that individuals with visual impairments must understand their own needs. Understanding their needs facilitated communication to others about what needed to happen to meet these needs. This ability to play a leadership role in meeting their own needs facilitated a comfort level among those individuals involved. Our son was looking forward to a trip to the Provincial Museum dinosaur exhibit. This tour had been prearranged and therefore my son understood that the museum was expecting a group of children with significant vision loss. Shortly after the tour started, my son realized that he was not able to handle any of the exhibits because they were behind glass or rope. He panicked. He questioned us about the access problem he was experiencing and wanted to know if we anticipated a change. When we confirmed for him that there probably was not going to be a change, he screamed, "I need to see the manager, I have a complaint". He lodged his complaint with the manager, who quickly arranged for him to spend the rest of the tour with the archeologist. As individuals actively pursue meeting their needs, they are in position of control over their own situations. Knowledge, good advocacy skills, and control over self are qualities that could be associated with competence.

Mary Ellen reported that, "the more skills you have the more flexible you'll be. Be sure to get your Braille skills down and your cane travel skills because if you've got those, if you've got Braille and basic literacy skills, then you can learn anything you need to learn." Skills to manage blindness may assist individuals with visual impairments to develop literacy and competence that would facilitate placement in the world of work.

Probably the most significant facilitating behavior, that all co-researchers discussed, was the presence of appropriate expectations and standards. The most rewarding and positive situations for them, in school, were those times when they were expected to achieve. Goals were established that they had to work to accomplish. They were rewarded appropriately for work they did themselves. The skills they had or were being taught facilitated literacy. They appreciated competitions and challenges. Ross recalled an experience he had with his wrestling coach where team members were invited to go long distance running with him. He revealed, "The time was set and if you weren't ready they went without you." Ross was told if he couldn't make the distance then he could stay home. He was determined not to be excluded.

It is important for teachers and parents to have some sort of measuring tool to assist them in establishing expectations. If they have no idea what it means to be a good braille reader they probably need some guidelines to make the judgment. These guidelines could provide some basis from which to develop goals. Situations, in which their parents and teachers took ownership and accepted a leadership role in developing or delivering programs, were rewarding for co-researchers.

Facilitating behaviors such as humour, fitness, and passion had very positive influences in the lives of the co-researchers. They discussed the value of high expectations and appropriate goals or standards. Wendy's story about the commitment of her mother exemplified the powerful impact that parents may have. All co-researchers revealed the importance of role models for individuals with visual impairments as well as their significant others.

The next section will discuss the global theme of feelings. This overall theme was present throughout all three themes and therefore could not be considered a theme unto itself. The impact of the feelings described is significant enough that it was important enough for them to be addressed in a separate section. The section on feelings describes the polarizing factors associated with feeling. The negative feelings are discussed first, followed by a discussion about positive feelings.

Negative versus Positive Feelings

Negative feelings in this study were associated with a situation that seemed burdensome to the co-researcher. The feeling was unpleasant and required some time to resolve. In essence, we could imagine the stage changing to an upward tilt. The positive feelings expressed by the co-researchers could be associated with the balance or downward tilt of the stage. The individual expressed excitement, interest, and fulfilment at these times.

A parent, teacher, or individual who experiences blindness for the very first time will more than likely have feelings associated with this experience. There is a good possibility that these feelings will be fairly negative and could include anger, grief, distress, sadness, depression, disbelief, or sorrow. I experienced many of these feeling during those times when we were facing blindness for our son. Wendy talked about blindness with respect to parenting and teaching. She said, "It's very difficult as a parent, when you have such an emotional reaction with a child with a physical disability and all of that blends into it. And teachers have a very emotional reaction knowing that they will teach a child with a disability. It's hard to get calm, to prevail all the way around." These feelings will be discussed in sections titled: parents of children with visual impairments, teachers, and individuals with visual impairments.

Parents of Children with Visual Impairments. When my son first encountered eye problems, we felt very scared and distressed. I attended a workshop about vision loss and listened to the presenter talk about parenting a totally blind youngster. I remember very clearly thinking, "That could never be me, I could never do that." Some individuals may interpret these feelings as denial toward the challenge that we were facing. As well, I remember riding my bike around town in the evenings feeling that somebody should pay me millions because of my son's eye disease. I was angry.

The co-researchers talked about their parents' experiences with medical personnel during the time that treatment was occurring for their children's eye disease. These reports revealed feelings of frustration and inadequacies. For example, Mary Ellen's mother noticed very early on that her eyes were not tracking properly. Family friends advised her to have it checked on and when she did the doctor told her that nothing was wrong. She did not believe this and pushed him to look again. This time he went down the hall and got an ophthalmologist who confirmed her mother's fears that something was wrong. Mary Ellen's mom could have been very frustrated with this situation because her instincts and knowing were not given fair due. Parents could be considered at risk when dealing with the medical profession for two reasons, (a) they are very emotionally involved, and (b) their expertise in knowing the child and therefore reporting symptoms or observations are often not given the appropriate level of credit. When doctors did not pay attention to my input during an examination, I felt very inadequate. I often assumed the identity of overemotional mother who was over-reacting to the situation..

Diana's mom may have experienced grief when she had to face the decision that her daughter would move away at the age of six. Diana reported, "When I was attending Jericho Hill my mom tried to spend a month in Williams Lake and then a month in Vancouver in order to visit with me. School policy dictated that since I was a dormitory student, it was too disruptive for me to be taken out during the week and therefore my mother could only see me on weekends. Thus, my Mom would travel the 300 miles to Vancouver only to sit in a hotel room during the week in order to see me two days on the weekend. She had to face the local school board meeting after meeting and make a case for them to allow me to come home and go to school. When the board finally agreed, they established conditions that placed a lot of responsibility upon her." One could assume that Diana's mom may have experienced moments of anger, frustration, depression or sorrow.

Ross's parents were very isolated in their small town. Specialists told them Ross had to move to go to school. They had no reason to dispute this fact. When he came back home, they had no contacts with anyone familiar with blindness to provide some direction or support to them. According to Ross, they remained relatively uninvolved throughout his school career. He felt they cared a great deal for him and there was no doubt that they would have stepped in if life threatening or serious events unfolded. Ross reported that his parents were not able to give him the tools to do well, basically because they didn't have them. Blindness was new to them. It's possible that his parents felt inadequate when having to deal with the blindness and therefore chose not to be involved.

Many parents have to face the negative attitudes of the general public specifically directed to their abilities as parents. For example, Mary Ellen talked of an incident when she was growing up, regarding swimming at the public swimming pool. The local swimming pool staff made the rule that she was only allowed to swim if she was accompanied by an adult. Her parents challenged the staff and attempted to educate and explain. However, she reported, "When the staff implied that they were being neglectful and uncaring parents, they got scared and backed off. And that was the usual pattern."

Blindness is a low incidence disability. As a result, parents with children who are blind, may find themselves isolated from other families with blind children. Feelings of isolation, and inadequacies may be reinforced because parents may not know what to expect from a child with blindness. They are not prepared to make judgments about whether behaviors they see are directly associated with blindness or not.

Teachers. Teachers may experience negative feelings, similar to those that parents experience, when they are first exposed to a student with blindness. I experienced anger the first time I had a student with severe disabilities in my classroom. I did not feel prepared because of lack of training, materials and support. Wendy talked about her high school days in Sedgewick and made reference to the fact that appropriate braille materials were very difficult to acquire, especially at the appropriate times. She reported that her teachers may have felt frustrated, anxious or inadequate. Ross shared that the teachers in Calmar didn't quite know what to do with him when he violated school rules. He stated, "If I got into trouble, I became a situation. The teachers would almost have to put their heads together and collectively decide what they should do."

Diana talked about her mother's experience trying to persuade the school board members to allow her to attend her home school. She revealed, "To compound the problem, neither the local board nor the Jericho Hill administration was particularly supportive of this move because of perceived political pressures (Jericho Hill was a new school and unless supported would close). Local school staff may have also been concerned because they felt inadequate dealing with the issues and concepts associated with teaching a child with blindness." Diana talked about experiences she had with teachers who admitted that they did not know how to teach her certain materials, especially those associated with visual presentation.

Individuals with Blindness. Some individuals with blindness experience pain as a result of their particular eye disease. My son was diagnosed with glaucoma. This eye disease can be very painful and he had a very extreme case. Pain was very real for him and very negative. For my son, his stage was so significantly tilted that his journey was arrested until the pain was controlled and he could again resume.

Wendy talked about the anger she felt when a school mate invited her for a sleep-over one night and later told Wendy that she was not allowed. The girl's mother thought that she might get lost in their house. Paul talked about the brutality that he experienced in his school. He reported an incident that occurred in the infirmary at the school. He and another boy were sick. It was the other boy's birthday and his parents, who were poor, had sent him a little statue. They weren't supposed to talk and when they did the nuns hit him over the head with a box and broke the other boy's statue.

Mary Ellen reported that she experienced feelings of frustration with blindness. She developed a core attitude about having to be perfect in order to be accepted. She talked of the embarrassment she felt when the principal of her school chastised some of the students with blindness for misbehaving in the classroom during quiet time. The principal referred to them as animals and suggested that if they were going to continue to act like that she would send them away. From that moment, she reported that she did not want to be associated with them and tried desperately to be sighted. At the time, she believed that if she really wanted to grow up, she would have to hurry up and become sighted. The feeling that she carried with her at this time was that she couldn't possibly grow up as a blind person and really be an adult. Mary Ellen won a regional junior achievement honour. In honour of winning this award the winner was invited to a National Conference held during the summer months on campus of a university in the United States. When the organizing committee realized that Mary Ellen was blind they sent her a letter stipulating that she would not be allowed to attend the conference with the others. Arrangements had been made for her and her parents to stay at a hotel close to the campus. Also, she could only attend if arrangements were made for someone to accompany her throughout the sessions. She was deeply hurt by this and reported that this offense demolished her self-confidence, "Because you know, my whole thing had been if you are just about perfect and better than everyone else, then you'll be accepted and here I'd been the best and I still wasn't accepted. And I, you know I didn't know what to do with that, I was just really afraid that no matter what I did in my life, that somebody who was ignorant could close a door in my face and I'd just be out of luck."

Ross expressed his feelings of resentment when he talked about graduating from high school and felt that he really hadn't learned anything. He equated this feeling to that of functional illiterate. He went into education at University just so he could get back at the system that he felt had failed him so badly.

Paul also expressed his feelings of frustration when he talked not only of going to a blind school but also going to a school that was French and not English. The School for the Blind was French. If he had been sighted, he could have attended an English school.

Embarrassment was another negative feeling that the co-researchers talked about in their interviews. Mary Ellen reported, "Every time I'd answer questions, she would praise me to the sky and so I stopped answering questions after awhile." Wendy stated, "I did not like to be shown up in any way or singled out in any way. I didn't like to do anything that wouldn't happen to other people. I didn't like to look lost, for example, or to look foolish, you know, to be perceived as pitiful."

Wendy recalled the feelings of loneliness and homesickness when she first arrived at Jericho Hill. "... suddenly I was in Vancouver. I cried for ages. I can remember thinking that I would discipline myself and I would get down to a smaller amount of crying each day."

Experiences, which generated positive feelings, were expressed by all co-researchers. These positive feelings included determination, pride, acceptance, confidence, common sense, courage, joy, patience, understanding, respect, and love. It appeared that negative challenges could be more easily accommodated and dealt with within the presence of these positive feelings. Examples of the experiences of positive feelings are discussed in the following sections under the headings: parents of children with visual impairments, teachers, and individuals with visual impairments.

Parents of Children with Visual Impairments. Mary Ellen and Diana discussed the determination that their parents demonstrated when faced with the challenges of their blindness. Mary Ellen reported that her mother challenged the doctor, telling him, "Yes, there is something wrong, look closer." Her report also included an example of her determination with the story about her mother getting together with other parents and lobbying the school system for a teacher of the blind. The school system wanted nothing to do with this request and Mary Ellen's parents were, "Literally evicted from the Superintendent's office and told they weren't welcome."

Diana's mother also lobbied the school system to have her child accepted in her home school. Diana reported that her mother worked toward this goal for approximately three years before they finally agreed that she would be allowed to enroll. In an effort to prepare Diana for school, her mother organized a preschool program for her. According to Diana, "She was not a teacher, she was a very practical housewife, who was bound and determined that if I wasn't going to be able to see, the things I did would have to be done with my hands, so I'd better be good at using them."

The co-researchers made reference to their parents using common sense in many situations. Diana's mother, for example, would see other children doing something and would figure out a common sense way for Diana to participate as well. According to Diana, "She involved me, life didn't happen around me."

Teachers. According to the co-researchers, the most positive influencing factor for teachers was one of acceptance. Those teachers, who accepted students with significant vision loss as one of their students, appeared to be more successful. The co-researchers discussed several teachers who accepted them. These teachers stood out in the minds of the co-researchers. These teachers took a special interest in addressing access and created activities within the classroom that allowed equal participation. Ross talked about a teacher in Calmar who was always willing. According to Ross, "He would spend every lunch hour going over math with me because I was failing . . . he was willing to give some time."

Ross indicated that his experience with teachers at Jericho Hill left him with the feeling that they were proud of what they did. He felt that they somehow viewed themselves as quite special.

Individuals. Co-researchers consistently reported that loving and caring families were very important. Co-researchers reported that, regardless of the level of involvement of their parents in issues related to the blindness, they were confident that they were loved and they felt like they belonged. Paul recalled the summer that his parents rented a lake property and he and his mother would spend the summer there. His father would join them on the weekend. He used to roam and swim and started to make friends with the summer families. His dad bought a boat so that he could learn to water ski. He recalled that this past summer he was able to model this skill for his own children. Doris talked about returning home for the summer months. She reported, "The family was always delighted to see me and I was always delighted to be home. I would just automatically take in and dig in and do my chores."

Discussions with the co-researchers revealed that negative challenges could be more easily balanced in the presence of positive feelings. Their experiences provided some insights into how these positive feelings were very closely associated with positive attitudes. When I asked Doris if she felt that the negative examples were too heavily emphasized in the theme discussions, she said, "Well no, everybody has negative experiences. They just happen and then they are over with, nothing to bother about." Through this comment, Doris demonstrated the strength of positive feelings and attitude.

Conclusion

The co-researchers, in this study, were found to be wonderful role models for children with visual impairments, parents, teachers, and the general community. They have moved through the challenges of blindness and maintained a balance to their stage that allowed them to continue to lead happy productive lives. The challenges of blindness were defined through the structures of their school experience. They appeared to be disconnectedness, lack of preparation, inhibiting behaviors, and negative feelings. The factors which provided stability, balance, and encouragement for them were discussed within each section. A summary of these positive factors is presented in the following section.

The introduction of this chapter discussed the structure of the stage of life. This stage is created from constructs such as beliefs and expectations. Our beliefs and expectations are driven by what we know is possible or from past experience. According to the co-researchers, the most rewarding situations for them were those where they were accepted on the same level as everyone else and therefore genuinely included. As an example, Ross said, ". . . I suppose I would like to just have been considered the equal of every student in the classroom . . . the groups I'm most comfortable with are the ones with people in the room that don't see me as anything special." In these situations, the individuals around them believed in them and expected that they make their contribution equally to the group as a whole. They respected high standards, enjoyed the thrill of competition, and praised those who pushed them. As they reflected about their school experiences, it became obvious that joy, humour, and fun were an integral part of their lives.

The development of skills to manage blindness was important to facilitate equal access and literacy. They were proud of their accomplishments and believed that competent skills afforded them more opportunities to excel. Ross, in particular, advocated for the necessity of establishing a balance in one's life between academics and physical fitness. Locating and promoting good role models was advocated by this group as necessary for educating the general public about the capabilities of individuals with blindness.

Ross discussed the idea of goal setting for children with visual impairments. He stressed the importance of recognizing and acknowledging the dreams of the child. For example, a child who dreams of being an aeroplane pilot should not be discouraged from dreaming and planning toward this. According to Ross, we do not have the right to interfere with individuals' dreams. He added that the spins off from such a dream could be very rewarding. For example, the prerequisites for aviation pilot are good grades and high school matriculation. If the child achieved high grades and matriculation and enrolled in aviation school, he may find out on his own that this was not his interest or there may be another way to become involved that would be more appealing. Ross and the others promoted "Dream the Dream" and they also encouraged parents, teachers, and significant others to grant permission to be blind to those individuals in their lives with significant vision loss.

The findings of this study was discussed in chapter four. Chapter five will contain information about the review of those findings, a discussion of the significance, and implications of this study.

CHAPTER FIVE

Discussion of Findings

Chapter four presented the findings of this study. The descriptions of the co-researchers' school experiences created an image of a journey across a stage. The stage represented a life path that is supported by a belief system that has been developed by acquiring knowledge and experiences along the way. A belief system, therefore, generates expectations about how day-to-day experiences will unfold. If the experience is as expected, the belief system is confirmed. Experiences that are different from expectations may enrich or change the belief system. Experiences that are different from what is expected may present as a challenge.

The journey across a stage where expectations are confirmed may feel manageable and comfortable. A challenge may influence a stage to tilt upward, making the journey considerably more difficult. According to Webster's New World Dictionary (1990), a challenge can be defined as, "a call to fight, a call to answer or explain, and a call to question or doubt (p.100)." A challenge, therefore, can be perceived as something that makes us work. The more significant the challenge the harder the work.

Challenges influence the acquisition of knowledge and the provision of opportunities for new experiences. New information or experiences may generate new hypotheses about these experiences and therefore change the belief system. A change in the belief system may influence or change expectations and behaviors.

As the co-researchers recalled their journey through their school career, they revealed the structures of their experience. These structures can best be described as the challenges they faced as a result of their blindness. Chapter four presented the challenges of blindness as: being unprepared, being disconnected, being influenced by inhibiting behaviors, and being negative. These challenges were described as influencing forces that created an offset or imbalance of the stage. Factors or influencing forces that rebalanced the stage to facilitate the continuing journey into successful adulthood were also presented in the discussion of each theme. Chapter five will include the discussion of, the significance of the study, the application of the findings, and the discovery.

Significance of the Findings

This study had a significant impact on my life. Participating in this study has changed my outlook and my place in the field of visual impairment and blindness. The words of Dick Sobsey's (1996) poem, My Child: An Introduction, best articulates my experience as a parent and professional.

My Child: An Introduction

When the little boy on the bus held back his tears,
people said he was brave.
When my child does the same thing,
a doctor tells me that "retarded children are insensitive
to pain."

When the little girl who lives next door fought for her
rights,
people called her assertive.
When my child does the same thing,

a behavioural psychologist tells me that "retarded
children are noncompliant."

When other children suffer,
people look for ways to make their lives happier.
When children like mine suffer,
bioethicists ask if it might not be better to end their
lives.

Professionals tell me that I am grieving
... grieving for my disabled child
... grieving for the loss of the healthy child that I wished
for
... grieving for something irretrievably lost.

I need not grieve for my child,
perfect in his own way.
My sorrow is for those who cast dark professional
shadows
and fail to see my child's light.

This poem represents experiences with children who have significant disabilities, from two different perspectives. I believe that as a professional working in the field of visual impairment and blindness, I practised my work from the first perspective. Participating in this study has facilitated the practice of my work from the second perspective.

The first perspective may be held by individuals who have never had close personal experiences with disabilities. Their expectations for this situation, therefore, evolve from a belief system that has been influenced by a lack of information or inappropriate information about disability. Possibly, they could have had uncomfortable or negative experiences which prevented them from hoping or believing that living with disabilities could have rewarding moments. The first perspective may also be held by those individuals who have had experiences with individuals with disabilities. These individuals may be informed but only consider or see the disability and forget about the individuals and their significant families. As a parent of a child with blindness, I have been involved with professionals that fall into this category. I felt a tremendous amount of pressure to have the appropriate levels of service, the right assistive technology, and the correct questions at the doctors' office. I allowed professionals to make decisions on behalf of children at the school level. We allowed professionals to accompany us to the doctors' office and ask the questions. We allowed professionals to tell us that the location of our home was not safe for our son and we should consider moving. When I asked doctors for information about whether or not I should be in contact with services or agencies, I was told they would tell me when it was time. They were going to decide when that time was going to be. At the time, I was accepting of this place, this position I found myself in. I was very dependent on the professionals involved in my life at this time. I felt that I was not in a position to challenge or question them because I was afraid of jeopardizing service(s) for my son. I focused on the perceived benefits to him and swallowed my own feelings and concerns about the situation.

My husband and I met a fine doctor in Boston who practised medicine from the second perspective. When we visited Dr. Walton we expected to be told briefly, in medical terms, about our son's condition. Instead, we met an individual who always talked about our home, our jobs, our other children. He asked so many questions about the other children he began to know them, even at that distance. He asked us how we were managing. He asked us what kind of support and resources were available at home. When we told him we did not have any information, he sent us the book, Can't Your Child See (1985), in the mail. In the hospital he had a reputation among staff comparable to a knight in shining armour. He left orders not to wake children at night. His orders always included items that would enhance the comfort and total well-being of the child and family, i.e., humidifiers by their beds, removing IVs before children woke, and allowing parents to hold their children as they came out of anaesthesia. He truly exemplified the second perspective in the poem.

The second perspective may be held by those individuals who have a belief system that has holistic knowledge and experiences with children who have disabilities. Prior experience or information could have allowed them to experience hope, love and joy in the moment. These individuals may have a belief system that allows them to interact with the individual first and the disability second. They have probably taken the time to celebrate small successes and capture the meaning in small moments.

These perspectives are important to the findings of this study because many of the negative challenges discussed throughout the results are associated with the first perspective. For example, my husband and I travelled to another city for medical treatment for our son and met doctors who failed to acknowledge our isolation because of distance and lack of support. They were expert in their professional skills but we felt disconnected. We met Dr. Walton, who validated our isolation, and we began to understand belonging. I went back to university and pursued a career in vision consulting to prepare for blindness. My efforts to prepare for blindness were not complete until I gained the understanding of the second perspective. This was facilitated by coming to an understanding of the meaning of the co-researchers' school experiences.

I have been involved in the field of visual impairment and blindness for the past seven years. During this time, I worked very hard to develop a level of expertise that would provide a high standard of service to children with visual impairments and their families. Over the years, I nurtured a philosophy that children with significant visual impairments must develop competent skills to management blindness. I believed that the direct return on the development of these skills was entry into society as an equal contributing member. My preparation as a professional in this field included the examination and development of materials available to teachers, parents, and support staff, to increase the awareness of competence in skill development. I also supported and promoted equal access to information. I worked very closely with parents and teachers to maximize access to information for children with visual impairments. I realize now, that I represented the sighted perspective. I was influencing and teaching children with visual impairments from the perspective of what I thought a child with visual impairments should be. Using the words of one of my co-researchers, perhaps I was facilitating the development of the "perfect blind child".

As a parent and professional, my involvement with children who are blind seemed inadequate. I was aware that, as a parent of a child with blindness, something was not quite right for me. My life felt out of control. I believed that information and involvement would arm me with the tools that I needed to gain back the control that I felt I had lost. I felt focused, determined and motivated to my cause of searching for something that would "make a difference". Making a difference seemed important to me because my experiences as a parent and teacher created challenges for me that felt very big. I believed that my involvement in the development of something to "make a difference" would ease the challenge.

This study taught me that my role as a professional in this field was not only inadequate but incomplete as well. I was so busy searching for the right materials, the right tools, that I forgot to ask myself, "What is important to my son?" and "What is important to children with blindness?" In essence, I was searching for the answer to this question from the wrong side of the fence. I needed to look for the answer from the other side, the side which considers the second perspective in Sobsey's poem. This side facilitates the practice of my work in the way that Dr. Walton has already perfected. This perspective looks at the person first and the blindness second. This perspective recognizes the importance of celebrating the small successes and the joy of the moment. Through this study, I've taken the time to pay attention to this question and realized that the right material, the right tool, would not make as significant impact as I had dreamed. My co-researchers have taught me that early intervention which provides support, early referral, and information, makes a significant impact. Also, the practice of inclusion to facilitate belonging and acceptance is important. They mentioned the significance of opportunities to facilitate concept development as well as opportunities to be challenged and to compete. All co-researchers talked of the significance of being rewarded for work that they did for themselves and having responsibilities. Finally, all co-researchers recognized and acknowledged the significance of dreaming the dream and having fun along the way.

My husband and I provide these things to our other children. There is the possibility that we may even take them for granted. With Ben, I believe these elements were still there but somehow the disability got in the way and prevented me from celebrating the successes and the joys of the moment. Perhaps, I have been so busy trying to make a difference for my son, I forgot about the importance of enjoying him along the way. I had to work hard to tame the challenge and rebalance my stage. The information from this study made me realize how much our son, and, experiences with blindness, have enriched our lives.

This study provided me with the perspective of the student with blindness. As I learned from my co-researchers, "There's no real status in being a perfect blind person." My co-researchers had a tremendous amount to offer. This study is significant because the insights of these individuals are very powerful and may not have been considered by parents and teachers. These insights may influence ways in which children with visual impairments are parented or taught.

The following section will discuss how the insights, provided by the co-researchers, could be applied by parents and teachers. These insights may help us get to the other side of the fence and see the "light" of the child with blindness.

Application of the Findings

The insights of the co-researchers included information which is presented under the following headings: early intervention, inclusion, opportunities for concept development and competition, rewards for work, dreaming the dream and having fun. The following sections will discuss each of these topics in more detail.

Early Intervention.

If we accept Tolman's theory of learning and accept the concept of the belief system developing from what we know to be, which has been generated by teaching, information or past experience, the importance of early intervention becomes significant. Information about blindness is necessary to prepare the stage and change the belief system. If individuals have had no experience with blindness, they can only imagine what that experience might be by simulating the experience for themselves. They close their eyes and imagine what it could be like. This experience may be terrifying and may leave them with the attitude that any level of performance is miraculous. The expectations an individual would hold about the abilities of persons with blindness, generated from such thoughts, may be much lower than they would be for a sighted individual. If the expectations are lower, the tendency may be to accept whatever level of performance one encounters.

Information about blindness in the areas of understanding blindness, the implications of blindness, and resources and support available for blindness, could have two influencing forces. One, information of this sort may influence a level of comfort with blindness which could foster the use of common sense and acceptance. Trief's (1992) pre-school curriculum may provide a comfort level for parents and teachers because it is a tool that reveals appropriate developmental milestones. Secondly, information and resources challenge the belief system about blindness and perhaps influence a change in the belief system to incorporate appropriate levels of expectations for individuals with blindness. Ferrell (1986) stated that access to information is critical in the early lives of children with visual impairments. Information and resources could be accessed through advocacy groups, service agencies and professionals trained in education of children with significant vision loss.

Advocacy groups and service agencies such as the CNIB, NFB-AE and the ASVI provide a wealth of information specific to the areas mentioned above. They work with families and professionals as advocates, mentors and specialists in the field of blindness and visual impairment. Skellenger and Hill (1994), Rettig (1994), and Troster and Brambring (1994) reported that the developments of children with significant visual impairments have been measured by sighted standards. Therefore, early referral to these groups is essential to parents and families who experience blindness for the first time.

Professionals trained in the field of blindness and visual impairment may play an important role in the dissemination of information. They have access to children in the school environment and can influence the educational team with their level of knowledge and wealth of resource information. They should model comfort level and should promote the development of educational plans that are based on appropriate expectations. They are in a position to empower parents and teachers to take ownership and control over the situation of parenting and teaching a child with visual impairments.

According to Tuttle (1984), the professionals must be motivators who can encourage the visually disabled person toward his/her potential. The professionals are active participants in the shaping and moulding of the self-esteem of the people with whom they associate. Effecting a positive change takes time, patience, and many positive experiences. Tuttle reported Lowenfeld's convictions about professionals in the field of visual impairment and blindness by saying, "most professionals tend to expect if not demand passive and compliant behavior" (p.80). Tuttle provided some guidelines for working with blind persons following these comments directed toward professionals. A complete listing of these guidelines has been included in Appendix 7.

Role models play a significant role in fostering appropriate expectations. Role models can serve two purposes. For some people, an effective role model could be an individual with blindness who has excelled or achieved at an outstanding level. An individual with blindness who climbs to a significant level of prominence may challenge the belief systems of those who believe that blindness creates an impossible situation. They open the door for what is possible and therefore influence expectations. Individuals with visual impairments need to be reassured that there are other visually impaired students like themselves who are undergoing the same kinds of experiences (Scott, 1982). Therefore a role model for individuals with visual impairments and their families could be an average, normal individual with blindness, i.e., someone who is living a normal life doing what we believe normal people do. These role models are perhaps the most powerful ones because they create a sense of normalcy for the general public which is difficult to deny. Individuals with significant visual impairments need to know about successful individuals with blindness (Scott, 1982). The success of the prominent individuals may run the risk of being accepted as an exceptionality.

Inclusion.

The notion of inclusion has been discussed for a number of years. Inclusion has come to represent a variety of situations depending on the interpretation of its meaning (Wilgosh, 1992). According to the information from this study, inclusion means the state of belonging. During this study, the state of belonging was discussed beyond placement in a program or classroom. The information within this study extended the state of belonging to include families, advocacy groups, social groups and the general community at large.

Belonging to a group means more than just being a part of the group (Wilgosh, 1992). It means that, within the group, there are recognition and acceptance from group members that the individual's place within the group is as valuable as anyone else's. Believing that an individual belongs and therefore is an integral part of a group is based on our belief systems. Thus, in order to facilitate change in attitudes of acceptance and belonging there must be a change in the belief system. According to Tolman's theory of learning, the belief system can be changed from experience or knowledge (Hergenhahn, 1988).

Acquisition of knowledge and experiences with role models were addressed in the previous section. These strategies may be effective ways to facilitate inclusion. Other strategies include the implementation of standards, assessment portfolios and definition of roles. These latter strategies are implications for practice and are in response to this study, not derived directly from this study. They will be discussed in the following section.

Presently, the provincial governments have standards for education. These standards address issues such as a curriculum in subject areas, qualifications of teachers, hours of instruction and boundaries of basic instruction. Boundaries of instruction provide directions addressing what you can and cannot teach, involvement of parents and school policies. Special needs students, in Alberta, are eligible for additional funding if they meet severe disabilities criteria which have been defined. School systems must also have supports in place to meet the needs of qualifying students in order to access the funding. According to the criteria, blindness is considered a severe disability. At least three, of a five, outlined levels of support are required. These could include three of the following: specialized technology or materials, teaching assistance support, consulting services, assistance with basic needs such as eating and toileting, and an individual program plan.

Standards establish a framework from which our expectations for the school system develop. We know what to expect when we send our children to school. Based on the standards of education, teachers are able to communicate with parents about appropriate levels of achievement in skill areas. Parents and teachers are able to make decisions about remediation or enrichment based on this ability to communicate. Chapter two presented a review of the literature outlining needs of children with significant vision loss. Parents of children with visual impairments, and the teachers of these children, do not automatically know what to expect in skill development in areas of skills to manage blindness. These skills could include braille reading and writing, use of assistive technology and travel skills. As an example, they do not have a cognitive picture of what a good braille reader would look like. There are no standards outlining how a student would be taught braille, for example. There are no guidelines specific to minimal hours of instruction, materials to be used or level of training of an instructor. There are no assessment criteria defining levels of competence. For this reason, parents and teachers do not have a baseline from which to discuss appropriate programming and level of success within the program. Children with visual impairments tend to be judged against themselves and all too often parents and teachers cannot clearly articulate whether or not the level of skill development is good or not. How could they? By what standard would they be making this decision?

According to the Committee on Public Education and Professional Practice (1993), the process of integrating students has created problems with implementation, lack of necessary support, failure to meet the needs of special education students, and lack of essential training. These opinions reflect the concerns surrounding the lack of standards for students with significant visual impairments.

I believe an assessment portfolio is a tool that could be developed, to provide teachers and parents with information regarding the development of skills to manage blindness. This tool would be structured to contain information about skills across a developmental continuum. Information in this form is familiar to teachers because it very closely resembles how teachers receive information about grade level curriculums. The curriculum outlines what skills should be taught at certain levels or grades. The portfolio would provide this information in skill areas specific to blindness. This sounds simple; why hasn't it been done?

There are many factors which may complicate this process, i.e., age of the onset of blindness. An adolescent blinded in a car accident may learn braille quite differently than a baby born blind. Also, blindness is not absolute. Individual needs specific to vision loss varies greatly. Some people can manage very nicely with large print and others require the use of braille. It would be unfair to impose standards of braille reading on a student who was occasionally learning braille as preparation for a potential deterioration of vision loss.

For these reasons, I propose that the assessment portfolio should be prepared in workbook format. Each workbook would contain the same information (developmental continuums in skill areas - braille, large print, travel and so on). Each student with visual impairments would receive a workbook. An assessment by a knowledgeable professional would indicate the student's present level of skill development. Direction and support regarding the onset could be a part of this document.

The workbook could also be used to collect work samples. Materials and resources available would also be addressed. There are many advantages of this workbook. Skill areas would be associated with levels of development. The workbook would provide information for teachers and parents specific to growth and development for the student. This information would empower them to become active team members in planning educational goals, and prepare them for visits from the consultant or specialist working in the field of visual impairment and blindness. For example, the workbook might define braille reading speeds associated with certain levels or ages. The teacher with this information could ask the consultant to assess the braille reading speed. This information could be communicated with parents. Their team is then in a position to make judgments about "good" braille readers. Parents and teachers would know if remediation or enrichment is appropriate or necessary. This judgment could be made because a framework to work from has been established. In essence, the expectations would have been set.

The workbook would follow the student from program to program. The workbook is different from standards because it does not define levels of support, materials to be used, minimum qualifications of persons involved with teaching the skills, or hours of instruction.

As parents, students, teachers, specialists, and teaching assistants come together to form educational teams, the roles of each team member should be clearly defined. These teams will be developing individual educational plans for students with visual impairments. If the roles of team members are not clearly defined, the team may suffer from lack of progress or conflict. During the process of defining roles of team members, it is critical to the function of the team that the principle of ownership is addressed. The principle of ownership maintains that students with visual impairments are one of the twenty or so students assigned to a particular teacher. Teachers are responsible for programming, assessing and reporting for the student with visual impairments in the same way that they are responsible for the other students. Teachers may require assistance with these responsibilities, which is why the educational team is in place. The team provides them the support, resources and comfort to accept this responsibility and to be successful at the same time.

This principle of ownership also applies to parents. All too often, parents may feel that specialists are so knowledgeable with the field of visual impairment and blindness that they know what is best for their child. The parents may not agree with the decisions because the decision may feel uncomfortable for their family. The decisions may have other implicating spinoffs for the family that the professionals may not be aware of. Families may not express these concerns for fear of creating conflict or loosing support from professionals. As a result, they go along with or accept decisions for their children that they have not made. These situations may temporarily be acceptable but may be very damaging for families over the long term. If parents are not making choices for their children and are not taking ownership over the implications of blindness they may never acquire comfort level or decision-making control within their families. Ross made a point in his interview to say, "my parents did not have anything to go by to help them make the decisions so they just went with what the specialists said." Paul stated that, "professionals have professionalized blindness so that individuals feel they have to be trained to be involved."

Wendy reported that her mom taught her most of what she knows about civil disobedience. She recalled,

> The first time I went to Jericho Hill, she went along. It was just before my twelfth birthday and she had always kept a very close eye on me. In a flurry

of last minute affection, she had filled my wallet with money and my purse with aspirin and cough drops. Most of my clothes were shipped by rail in a trunk and my suitcase was full of food from home.

We were greeted at the dorm by a very officious teacher who explained the house rules to my mother. All money was to be given to her for safe keeping. Students were not permitted to keep any kind of medication. Sickness was dealt with by the nurses at the school infirmary. All food was pooled in the playroom and shared among everyone. om said very little. When the teacher finally left us alone she told me to eep my purse closed and make sure to share my food with my roommate.“These rules,” she said, “are for people who can’t be trusted with money and medicine. They’re for people who don’t know how to share.”

Mom stayed five days with Aunt Winnie. By the time she left for Alberta, Vancouver area students were already asking if I could spend weekends at their homes. My mother was supposed to sign permission every time I spent a night outside the school. She said, “That’s silly. I don’t know these people and I can’t give my permission. You will have to make the decisions and I will trust you.” She wrote the school a letter to that effect and they let me go out with whomever I chose. If Mom had seen some of my choices, she would no doubt have approached the issue with a little more caution.

The role of the teaching assistant is important to define. Doris stated that, "too much is done for them, they don't learn how to take care of themselves". If teaching assistants are not given the appropriate support and direction, they may feel that they have to sit with the student. The perception created by this physical placement may reinforce the notion that these students are not able to do things on their own. Also, it makes it too convenient for teachers and parents to communicate with the teaching assistant and not the student. Situations such as those described create a dependency triangle. The student becomes dependent on the teaching assistant and may not even recognize the teacher as the teacher. The teacher becomes dependent on the teaching assistant and may feel less responsible for this student,because the student is taken care of or the assistant understands working with visual impairment more than the teacher does. The teaching assistant becomes dependent on the student for job security or fulfilling the need of being needed.

Alberta Education has published a resource titled, Programming for Students with Special Needs (1995). This resource outlines roles and responsibilities of educational team members.

Opportunities for Concept Development and Competition.

According to the co-researchers, it is important for children with significant vision loss to have the opportunity to experience life in as many positive forms as possible. An abundance of life experiences could means that individuals have had support and influences from individuals with strong values and positive intrinsic qualities. These influences enhance the prospect of developing a positive identity

(Mitchell, 1992). Life experiences such as recreational activities, fine arts, crafts, or trades work will enhance their lives in many ways. First of all, participation in these activities will better prepare children for making decisions about where their interests lie. Secondly, it informs them about activities or hobbies that other individuals might be enjoying. Finally, exposure to many activities facilitates the development of a rich vocabulary, an asset because it provides a better opportunity to grasp concepts when exposed to a variety of individuals in different settings. Individuals may describe the same concept using different words.

Cultivating an interest and providing opportunities for that interest to grow into a passion will facilitate social interactions with individuals sharing the same passion. Groups of people joined together by some common interest find ways of getting together and enjoying one another's company and common interest. Children with significant vision loss miss the opportunity to visualize how individuals around them are interacting. They do not have the advantage of watching how other children enter play situations. They may not be aware of what other people are interested in, unless they have many different experiences. A variety of experiences provide them with a wealth of information which helps make them interesting people.

Developing an interest and passion also provides individuals with the opportunity to find out where their individual strengths lie. This discovery allows them to develop their gift to a level where they are able to compete. Competition reinforces a sense of accomplishment for oneself, if the competition provides us with some measurement of growth in a skill area. To compete with one's peers also reinforces a sense of belonging and contributes to the development of a positive self image. There is a great deal of pride associated with setting goals and competing with others or self to meet those goals.

Rewards for Work.

Mary Ellen revealed, in her Report Card for the Teacher (1988), the importance of rewarding students for work that they do themselves. A copy of this report card has been included in Appendix 8. Her report card grades her teacher, Mrs. Brown, in areas of language arts, independent travel and attitudes about blindness. She thanks Mrs. Brown for never forgetting that blind kids always grow up needing to know more from life than pats on the head from indulgent adults. She acknowledges that Mrs. Brown loved her enough to insist that she respect herself and earn the respect of others. Rewarding children with significant vision loss for ordinary behaviors give them the message that they are not capable. Ross graduated from grade twelve resenting this kind of treatment. Children with significant vision loss should be assigned responsibilities commensurate with their sighted peers. They should be rewarded at the same level as their peers. They should also suffer the same level of consequences from making bad choices.

Ruby Ryles won the 1992 Outstanding Teacher of Blind Children award and has published a teacher's creed. She stated,

> It is my task to show families that there is nothing unusual about a blind child leading a normal life - washing dishes, learning to skate, walking to school, cheer leading, etc. Although friends, teachers and others around her will

> consider her extraordinary when she does the most commonplace things - My, she does that well for a blind child - the family and the child should never measure her accomplishments by this false standard. I must help them understand the ceiling this attitude puts on the youngster's true potential (p.1).

Simpson (1986) reported that it is the school's responsibility to prepare youth for personal, social, community, and vocational transition into adulthood.

Dreaming the Dream.

Parents of children with significant vision loss more than likely are not in position to be dreaming good things about the future of their child with visual impairment. Scott, Jan, and Freeman (1985) introduced their book by acknowledging those parents with children who have significant vision loss have many fears. Some of the questions frequently asked by parents at early visits by counsellors include,

> What are children with little or no sight really like? Can they grow and develop like other children? Where do they go to school? Do blind people ever get married? Can they work and earn a living? Do they live in world of darkness? Can they be happy? (p. ix)

These questions may indicate that parents of children with visual impairments are very concerned and maybe even frightened about the future. They may not be in a position to be dreaming good things about the future. Ruby Ryles (1996) reported that she believed her job as a teacher of children who are blind is to encourage them to dream the dreams of the young, while instructing them in the nature of discrimination and the very real impact it can have on their dreams.

Parents require some measurement tool to reinforce that their children with visual impairments are developing globally at a rate consistent with their sighted peers. I always had a sense that my two oldest children were doing the things they should be doing because I could see my friends' children doing the same things. I was constantly comparing. Blindness complicated this process for me because I had no one to compare situations with. I was confused by behaviors I saw. I didn't know if they were behaviors associated with blindness - which I thought I automatically had to accept - or behaviors associated with my son's personality, which possibly needed to be put in check.

During my son's grade one year, his teaching assistant videotaped various elements of that year. Physical education class, braille reading, playground activities, recess, and getting to the school bus, are a few examples. This videotape was edited so that it showed little portions of each activity from the beginning of the year to the end. This video clip was matched with Rick Hansen's theme song, St. Elmo's Fire. The tape was given to my husband and me as a gift at the end of the year.

This tape did two very important things for our family. First of all, it showed us that our son was just like the other kids in his class. He was doing the things that the other kids were doing. He belonged. Secondly, the tape showed us that he was happy. What a wonderful gift! Professionals must try to find ways of providing some kind of measuring tool for the parents of the children they work with. This measuring tool assists parents to establish a comfort level and facilitate the development of appropriate expectations. A comfort level and appropriate levels of expectations allow them to begin to dream about what the future holds for their children.

Ross was quite adamant when he made the statement, "You have to pay attention to the dreams of your children and hold onto them" (p.17). He felt that it was not anyone's right to take dreams away from anyone. For example, when I was involved with a family several years ago, I was given explicit instructions from the mom, not to tell her daughter that she would never drive. As this little girl had no hope of having vision restored for her, driving seemed to be an impossible and unrealistic goal. My colleagues and I thought that the mom was in denial about disability. We did not understand her request. According to Ross, this little girl would find out on her own that driving may not be something that she wants to do. Finding out for herself may have many positive spinoffs however, and as a result, by the time she has discovered that she does not want to drive she may benefit from the preparations she underwent for driving.

Having Fun.

Tuttle (1984) reported that a person's sense of humour is a critical determiner of the quality of the adjusting process. He continued to report that humour can serve to break the awkward tension felt by the sighted. Tuttle (1984) stated, "The ability to laugh at oneself, to laugh at the ridiculousness and the incongruities of life, is both an indicator and a facilitator of good adjusting" (p.241). The co-researchers for this study shared many humorous stories from their school experiences. These stories were a reflection of many of the fun times they had when they were growing up. Humour and fun were a part of their school experiences. I was fortunate enough to be in the audience when Diana presented a keynote address at a conference in Calgary in November, 1996. Her delivery was full of humorous childhood anecdotes which delighted the audience.

My journal entries revealed many humorous anecdotes that our family has experienced. For example,

> Thanksgiving, 1996.
>
> We are seated at the dining table for a festive turkey dinner. The candles are lit and we are all seated preparing to say grace. There is gentle music in the background. The ambience is set for a truly wonderful occasion. Just as Roy was about to start grace we heard from the kitchen area - "Hey, where is all the food?" Temporarily, in horror, we all realized at the same time several things; (a) we were about to start without Ben; (b) no one had noticed; and (c) no one told Ben we were eating in the dining room and he was sitting at his place at the kitchen table (as he normally does when he is called to dinner). Following the initial moments of horror at what had occurred we all broke into laughter and accepted the teases from Ben. We began our dinner with grace acknowledging how truly thankful we all were to be together.
>
> Safeway, November, 1996.
>
> Roy and I are shopping with Ben at Safeway. He is not happy with us and appeared grumpy. At the till, the clerk notices his disposition and chooses

> to engage him in conversation. She scans a bag of brussel sprouts, looks at him and says, "You're having vegetables for supper tonight?"
>
> Ben replies, "I hate vegetables."
>
> She then says, "Oh, but vegetables will improve your reading."
>
> Ben says, "How?"
>
> She says, "They improve your eyesight."
>
> Ben, "I can't see."
>
> At this comment she crouches to his level, uses both her hands and gestures with her index fingers towards each of her eyes while saying, "Sure you can, what do you think these are?"
>
> At this particular minute, she has the opportunity to see the lack of visual response from our son's plastic eyes. She slowly redirects her gaze upwards toward Roy and me, who are grinning like Cheshire cats. Quickly she jumps up and looks around to see who else may have witnessed her move. We joined Ben in assuring her that she was very funny and she made our day.

The co-researchers generally agreed that an important part of their school experiences were the fun times that they had either at home, in the community or at school.

This study revealed the structures of school experiences of successful blind adults. These experiences were presented as challenges of blindness. Important factors that provided some assistance in overcoming or managing challenges was also reported. This chapter discussed practical application of the findings from this study.

As a researcher, parent and teacher, I have learned a great deal from this study. As well as having learned something from this study, I believe I have also made a discovery.

The Discovery

As discussed in the previous section, this study was significant because it presented school experiences from the perspective of individuals with blindness. The insights from these individuals were addressed and suggestions about ways that this information could be utilized or implemented were presented. This study caused me to look at my place in the field of visual impairment and blindness. I examined my position as a parent, a teacher and a consultant for individuals who are visually impaired. I felt excited about the prospective of having learned so much from this study and believed that it created the opportunity for me to become more complete and well-rounded in my work and as a parent. As I completed this final chapter, I believe that this study has done more for me than just offering me another perspective. I have made a discovery. This discovery has changed the ways that I parent, teach and consult to families with children who have special needs. The following section will discuss my discovery.

As a Parent

When Benjamin was much younger, he had a very difficult battle with glaucoma. The pain from this disease was extreme and he was not able to participate in life. When he was not screaming, he lay with his head coupled in his hands. He could not eat and only slept when exhaustion overcame the pain. My husband and I had to restrain him four times a day to administer medications. He underwent 31 eye operations, most of them in Boston. We therefore travelled extensively. Many of those times Benjamin was quite ill. During this time, my husband and I had many challenges. During Benjamin's severe screaming times, we would sometimes scream at each other or at our other children. We were not getting much sleep. I quit my job. I worried about Benjamin and our other two children. I felt I needed to do something for them but I did not know exactly what it was that I needed to do. I felt so caught up in his situation.

One day, while out running, I decided that I would write a children's book from Benjamin's perspective. I wrote this book as if Benjamin was reflecting about events our family had participated in and how these events unfolded. He queried whether or not he was responsible for the outcomes of each situation. The final message of the story was Benjamin's recognition of the specialness of his brother and sister. Benjamin queried whether or not this had something to do with him. A copy of the text from this book has been included in Appendix 9.

At the time that I wrote the book, I believed that our family situation was enriching the lives of my children. I thought the book would serve as a vehicle through which their specialness could be acknowledged. I believed that this book could serve this purpose. I also believed that the message would have had more impact if I had become more directly involved in the delivery of the message. I was aware of the specialness of my children and the changes that they were undergoing. I was prepared to share this testimony with the world and I realize now that I did not take the time to ensure that I shared it with them personally first.

This study has changed my perspective about my relationship with my children. Our son has provided the opportunity for us to reexamine our values and our relationships with people. He has taught us the value in communication. He has forced us to slow down and spend time with one another. His leadership as an advocate has given us the strength and courage to express our feelings and ideas. He has provided the opportunity for our family to become involved with each other and the community. My role as a parent has been affected because my co-researchers provided the insights that allow me to capture those elements of my childrens' lives that I may have been missing. I will pay attention to them as individuals and enjoy every moment that I have with them. I will celebrate the successes and enjoy the small moments.

As a Teacher

I have participated in many planning meetings where individual student programs were being developed. The purpose of these meetings was to develop appropriate educational programs for children with disabilities. The main objective during these meetings was the identification of goals for the upcoming school year. Typically the majority of these goals were in areas where children were experiencing delays or difficulties. The goal would be set and methods of implementing and assessing progress toward the goal were established. If these plans were followed, the child could spend a great portion of each of his/her school days involved in activities where he/she was having difficulties.

I have taught in a classroom where children that are very skilled at an activity were told, "Let someone else have a turn." I have delivered my programs from a mind set that dictates the maintenance of a sense of balance in the classroom. I was most comfortable when children were moving along within specified boundaries. Everyone was guaranteed equal participation and opportunity. This study has taught me that this perspective did not provide the opportunity for children to spend enough time doing the things that they were good at. I was not providing them the opportunity to excel in their gifts. Individual program plans should specifically address areas of strength and incorporate goals that would allow students to utilize these strengths. As a teacher, I have learned that I need to be more diagnostic in determining where individual strengths lie and therefore provide more opportunities to develop those strengths.

As a Consultant

This study has taught me the value of my own experience in the field of visual impairment and blindness. I believe that my role as a consultant for the visually impaired will change significantly because I am better prepared to consider all of the many factors associated with wellness. I am better prepared to encourage parents to enjoy their children and celebrate the small successes and enjoy the small moments. My experience as a parent will, hopefully, provide them with a source of courage to maintain control within their families and challenge professionals if they feel inclined to do so.

The most important influence this study has had for me in the field of consulting is the belief that the message delivered from this study is generic in nature. I believe that the concepts of early intervention, inclusion, opportunities, dream the dream and humour pertain to other disabilities as well as vision loss. I see the benefits of these insights serving all special education programs.

Conclusion

I mentioned previously that my professional career could best be described as a journey in search of the right materials or right tool that will make a difference in the field of educating children with significant vision loss. This study has provided the opportunity for me to experience a sense of self fulfilment that is very difficult to express.

This was a study of human experiences. Within those experiences human values and feelings were considered. Individuals who are involved with significant disabilities may be so focused on the disability that the human values and feelings may not be considered. Working with children with significant disabilities from of perspective of looking at the individuals and significant others first, and the disability second, will truly make a difference.

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APPENDIX 1

Definition of Terms

Braille - a standardized tactile method of reading and writing for the blind, including symbols or groups of letters to represent letter combinations or whole words. This system is known as Standard English Braille Grade 2 and is differentiated from "Grade 1 Braille' which is a descriptive term referring to the Braille alphabet and basic punctuation.

Large print - print size of 18 point or large

Low vision - term used to denote those who can usually be educated to varying degrees through their visual sense

Blind - visual acuity of 20/200 or less in the better eye with best correction or a visual field which subtends an angle no greater that 20 degrees. A majority of people with vision below 20/200 have some usable vision, if only the ability to distinguish between light and dark.

Visual impairment - a visual disability which even with correction, adversely affects a child's educational performance.

Compressing speech - speech which has been compressed in time, time-compressed speech or accelerated speech. Voice pitch may or may not be altered.

Synthetic speech - computerized reproduction of phonemes into words based on a variety of programming formats

APPENDIX 2

Matrix: Needs of Children with Visual Impairments

Educational	Access to Info	Parent/Comm	Early Inter.
specialized skills	materials	safety	
travel independently	teaching style -position -presentation -experiences -giving information -speed of working	mobility	increased population
concept development	access to curriculum	expectations	learning begins at birth
multi-sensory approach	assistive technology	networking	concept develop.
communication	level of support		access to info
social/emotional			
career/vocational			
environment -lighting -tactile skills -production of materials -decor -orientation to room -sound			
daily living skills			
assessment			

APPENDIX 3

LETTER TO CNIB AND ASVI

July 31, 1996

Mr. George Tribe
President
Alberta Society of the Visually Impaired
Box 72063
Ottewell Post Office
Edmonton, Alberta
T6B 3A7

Dear Mr. Tribe,

As you know, I have been actively involved with the ASVI for a number of years. I am aware of your work and familiar with the population that you serve. As a graduate student at the University of Alberta, Edmonton, I am preparing to research the childhood school experiences of successful adults with blindness. I require the names of successful adults with blindness who may be interested in participating in this study. My plan is to interview these individuals and discuss their school experiences with them. It is my hope that your organization will be able to nominate individuals who may be interested in participating.

The individuals that you nominate must have experienced some portion, if not all of their schooling as a blind student. The criteria for the selection of participants was developed from the literature on successful transition into adulthood and Tuttle's (1984) work in the area of success and self-concept. I am looking for successful adults with blindness. The educational perspective defines successful adults as individuals who demonstrate personal, social, community, and vocational adjustment. A personal perspective as outlined by Page and Cole (1987) and Tuttle (1984) suggested that successful adults demonstrate a solid identity with the blind world. As a result they have developed skills that provide them with the ability to access information from the sighted world. Based on this information the following criteria will be used in the selection of co-researchers:

- Personal adjustment - demonstrated ability to manage daily living skills and skills associated with routine home chores;
- Community adjustment - demonstrated ability to travel through one's physical enviroment safely;
- Vocational adjustment - demonstrated ability within a vocation;
- Social adjustment - demonstrated ability in a variety of recreational activities or hobbies, and

- Specialized skills - demonstrated competence in reading and writing skills that provide them equal access to information commensurate with sighted peers.

It would be very helpful to me if I had the names of nominees prior to the end of September, 1996. Thank you for your assistance and support with this project. If you have any questions or concerns regarding this request, I would be happy to discuss them with you. I can be reached at the following:

67 Woodside Crescent
Spruce Grove, Alberta
T7X 3E6

Home # 962-8128
Work #672-6131

I look forward to hearing from you.

Sincerely,

Dianne McConnell

SCHOOL EXPERIENCES OF SUCCESSFUL ADULTS WITH BLINDNESS

PURPOSE OF STUDY

The purpose of this study is to examine childhood experiences of successful adults with blindness. I am interested in analysing the meaning of these school experiences and determining if they are associated with the development of sucessful adults.

METHOD OF STUDY

I will interview successful adults with blindness and discuss their school experiences with them. Focus areas to be discussed include, demographic information, history of blindness, educational history, special accomodationsor modifications, and feelings associated with this, recreational and leisure experiences and feelings associated, experiences with acquisition of daily living skills, peer relations, and general feelings about the education of children with significant vision loss. The interviews will be scheduled for approximately one hour, however, it may be necessary to interview more than once. Information acquired from the interviews will be shared with the research participants.

Interested participants will be required to sign a consent form. Research participants may withdraw at any time and any information shared prior to the point of withdrawal will not be shared without the participants permission.

FINDINGS OF THE STUDY

The research findings will be shared with research participants.

CONTACT

Dianne McConnell
67 Woodside Crescent
Spruce Grove, Alberta
T7X 3E6

Home #962-8128
Work #672-6131

APPENDIX 4

Letter of Consent

Co-researchers name:________________________________

I ___________ agree to participate in the research study conducted by Dianne McConnell. Mrs. McConnell has reviewed the purpose of the study, issues of confidentiality and my role in this study. I am aware that I am free to withdraw at any point during the study. I am also aware that Mrs. McConnell may use direct quotations from our interview(s). I give her permission to do so.

Date:__________________

Signature of co-researcher:___________________________

Signature of researcher:______________________________

APPENDIX 5

Interview Guideline

1. Demographics

2. Take me back to your school days and walk me through what it was like for you.

3. Did you like school? Why or why not?

4. Talk about the most memorable event- good or bad. Why?

5. What worked for you, what did not?

6. If you could change something about school, what would it be?

7. If you could have chosen where to go to school where would you have gone?

8. How were your parents involved? What kinds of things did they do? How did you feel about this?

9. Describe some of the different feelings you had about school.

10. If you were speaking to a group of young children with visual impairments, what would you tell them? Their parents? What kind of message would you leave them with?

11. What is the most important thing you learned in school?

12. Talk about one person(s) who had the most influence on you?

13. What do you feel were some barriers for you? How did you overcome these?

14. Is there anything you didn't do in school that you wished you would have?

15. Most rewarding aspects of school, most distressing.

16. Is there something that you wished I had asked you about?

APPENDIX 6

Ethical Considerations
(Patton, 1990)

1. Promises and reciprocity: what is in it for the interviewee? Why should the interviewee participate in the interview? Do not make promises you can not keep.

2. Risk assessment: In what ways will doing the interview put people at risk? Consider, psychological stress, legal liabilities, ostracism by peers, program staff, or others for having talked, and political repercussions.

3. Confidentiality (what are reasonable promises of confidentiality that can be fully honored?)

4. Informed consent.

5. Data access and ownership (who will have access to the data and for what purposes?)

6. Interviewer mental health - how will the interviewer be effected by conducting the interview, what will they hear or see that may merit debriefing and processing.

7. Advice - who will be the researcher's confidant and counselor on matters of ethics during the study? People in interviews will tell you things they never intended to tell.

APPENDIX 7

Guidelines for Working with Blind Persons
Tuttle, Dean (1984) p.281-283

1. Blind people are, first, people with the same basic needs of love, acceptance, and feelings of worth as everyone else.
2. Perceiving a world without vision is a very real and valid experience. The nonvisual interpretation of the social and physical environment must be accepted and respected without unnecessarily imposing a visual frame of reference.
3. Emphasis should be placed on the positive, the "I cans'," the abilities, and the assets while at the same time maintaining a realistic perspective regarding any possible problems or limitations.
4. Instructions must be articulated clearly, without relying on facial expressions and body language to convey meaning. Occasionally it may be necessary, with the blind person's permission, to manipulate his body or body parts to demonstrate the desired motion.
5. Visually impaired persons must be encouraged to accomplish tasks independently, with intervention only when necessary. Occasionally this will require extra time, especially when newly acquired skills are being employed.
6. Visually impaired persons like everyone else needs the encouragement provided by praise for genuine accomplishments and tasks well done. However, false praise for achievements that are ordinary or routine can be detrimental.
7. Significant others need to formulate and carefully maintain realistic expectations that are commensurate with the blind person's abilities and skills. Blindness should never be used as an excuse for unacceptable behavior. The same behavioral standards should be applied to the blind and sighted alike.
8. Visually impaired persons must learn to set realistic aspirations based on a thorough understanding of interests and desires, strengths and limitations, abilities and inabilities, acquired and potential skills, viewing and not just as they relate to blindness.
9. Visually impaired persons rely on candid and honest feedback from others to determine the social acceptability of their appearance and behaviors.
10. Questions about vision, sex, careers, relationships, and so on. Require frank and accurate responses. When the information requested is not known, a simple acknowledgment of that fact and an expression of a willingness to find someone who does have the desired information would be helpful.
11. Conversations with visually impaired persons should be natural. There is no need for shouting and no need to avoid visually oriented words such as "look" and "see," as they are also part of a blind person's vocabulary.
12. When a sighted person is approaching a visually impaired person and it is not immediately apparent what, if any, help is desired, the blind person should simply

be asked. Frequently problems can be solved with the application of a little common sense, and usually the simplest approach is the best.

13. Active involvement in the community social, recreational, and civic affairs facilitates fuller assimilation. Personal and social competence is more important than anything else to achieve better integration into the community.
14. Anyone working with the visually impaired must become aware of his own feelings and attitudes toward blindness and resolve any problems before inadvertently communicating negative or derogatory attitudes.

APPENDIX 8

A Report Card for the Teacher

Mary Ellen Reihing (1988) p.104-118

"After all these years one of my cherished childhood dreams is coming true. I remember all those times at the end of every quarter when I waited nervously for that manila card with the letters on it that would determine my future. It's my turn now. So, just for you, Mrs. Brown, here is a report card for the teacher."

Language Arts

Thank you for calling yourself a "braille teacher," not a "vision teacher." Your terminology emphasized a skill I could learn, not a sense I would always lack. **A+**

Thank you for teaching me to use a slate and stylus in the first grade, even though I grumbled at the time. You should probably have hidden that Perkins Brailler until I was older, but your performance was still above average. **A**

Thank you for telling me that you read braille slowly because you tried to use your eyes to do it- not because braille was slow or inferior. It was neat to think that I could become better at reading than my teacher.

You did such a good job of protecting me from the stereotypes about braille that I was in college before anyone told me I would never be able to read faster than sixty words a minute. Since I already read at, more, than three times that rate, it seemed a little late to slow down. By the way, thanks, too for insisting that I use both hands to read braille, which is why I read so fast. **A+**

I wish you had found a term other than "going to out class" to describe the time we spent in class with sighted students. "Out class" sometimes felt like "outcast." **C**

I wish you had told me that the library for the blind had braille books and not just talking books. I wish you would have helped me learn how to order the books I wanted. It was fun being surprised by what the library sent, but I was in college before I knew that I could make my own requests. **D**

Thank you for making me learn to type and for not being fooled when I tried to waste the time allotted to my typing lesson. At least, you weren't fooled most of the time. (I wish I could blame you for the fact that I still hate to type, but I can't. If I could, you'd get and F.) **A-**

Independent Travel

Thank you for forbidding me to shuffle my feet and hold back when someone was leading me. **B+**

Thank you for insisting that I walk around the school independently. **A**

Thank you for making me learn to run when I was scared. **A**

I wish someone had told you about cane travel for children and you had found a way to see that I had learned it when I was younger. Maybe then I would not have smacked into a wall and broken a front tooth while playing tag. Maybe I could have done things after school with my friends on the spur of the moment and taken the bus home alone afterwards. I did a lot of things with my friends in school, but I always had to plan them in advance. **C-**

Attitudes About Blindness

Thank you for trying to protect us from the pettiness of the principal who didn't want us in her school. We still found out that she didn't care for us but it didn't matter as much because we knew you did. **A**

I wish you had helped me meet blind adults. I was afraid that if I couldn't find a way to stop being blind, I'd have to go on being a kid forever. **D**

Thank you for never forgetting that blind kids always grow up needing to know more from life than pats on the head from indulgent adults. Thanks for loving us enough to insist that we respect ourselves and to earn the respect of others. **A+**

"That's your report card Mrs. Brown. You passed. You should be promoted. So should your common sense ideas."

APPENDIX 9

I Wonder If It Has Something To Do With Me?

My name is Benjamin John. When I was one year old, the doctors found out that I had a disease in my eyes. The disease has been very painful for me. I have had 23 operations and I must travel a long way to another city where I go to the hospital. I am almost blind now and I may someday lose my eyes.

I have a Mom and Dad; a sister Maren and a brother Erik.

Maren is 10 years old and she is in grade 5. Erik is 5 years old and he is in grade 1. I am the baby of the family.

I think something bad must have happened in our family. Everyone seems so angry.

I wonder if it has something to do with me?

My head has been hurting for a long time now. I can't sleep and I don't want to eat.

I think Mommy is angry at me because I don't eat my supper.

I hear Mommy tell Maren that she needs her to play with me. I am really excited because she is so much fun to play with. Sometimes she gets upset when Mommy asks her. Maybe I should stop pinching her.

I have to spend a lot of time in the hospital. Mom, Dad and I get on a plane and travel to a hospital far, far away. We are gone a long time. Maren and Erik stay at home with friends.

When we were, away friends went with Maren to her spring concert and took Erik to his swimming lessons. Maren and Erik wish we were at home. When they are angry, I wonder if it has something to do with me?

I heard Mommy talking to Erik's teacher. The teacher told Mommy that Erik was lonesome and needed a hug when we were away. Mommy cried! I thought it was really nice that Erik wanted to hug his teacher.

Restaurants are not a fun place for me to visit. My family must think they are; they always want to go. I have a hard time seeing so I must touch to find out what is around me. It is noisy so I cannot tell where the sounds are coming from. We never stay for a whole meal. No one seems to have a good time. I wonder why we keep going back? I wonder if it has something to do with me?

My head was hurting me badly and I was crying and crying. It was late at night. Mommy and Daddy were with me. Maren got out of bed and told Daddy that she couldn't sleep. Daddy got angry at her. She went to her room crying. Mommy and Daddy spoke loudly to each other. My head did not feel any better.

I love to listen to music. Mommy puts music on the stereo and dances with me. I wish we could do this all the time.

I love to go outside too. Mommy has painted bright orange stripes on the steps so that I might see them and not fall. We spend time touching the trees and grass and listening to special sounds. Maren and Erik push me on my tricycle. This is so much fun. I'm so happy that my family enjoys music and the outdoors as much as I do. I wonder if this has something to do with me?

Lots of people come to visit us. Sometimes they bring us food so that Mommy does not have to cook. I'm so glad there are special people in the world to make my Mommy and Daddy happy. I wonder if this has something to do with me?

I keep hearing everybody say that I'm doing really well. I wonder why they say that about me? Do they say that about Maren and Erik? If they don't say that, I think they should. Maren and Erik and my Mommy and Daddy do really well also. I am so happy that I have them to take care of me.

I am proud of my family. They are special!!! I wonder if this has something to do with me?